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**ABSTRACT**

This guide was developed to help Wisconsin agency assessment, evaluation, and planning personnel to develop a perspective on how needs assessment fits into their state's vocational rehabilitation program planning. Volume II provides state agency personnel with tools for conducting rehabilitation needs assessment. The first three chapters consider the requirements and meaning of the legislative mandates for services at both the state and federal levels; a definition of the target population or program; the vocational rehabilitation program structure in relation to the total state service delivery system; past management decisions for resource allocation relevant to program delivery; availability and quality of current information on needs; and the agency's purpose, intended use, and resources for conducting a needs assessment effort. Chapters 4-18 discuss the following topics: needs assessment, for special populations (individuals with severe handicaps, chronic mental illness, developmental disabilities, specific learning disabilities, traumatic brain injuries, blindness and visual impairments, deafness, youth in transition, minorities, Native Americans, women); and for designated services in rehabilitation facilities, supported employment, independent living, and rehabilitation engineering. Appendixes include a 174-item bibliography with a list of selected technical references, a suggested format for a needs assessment report, and the addresses and locations of clearinghouses and secondary data sources, names and telephone numbers for contact persons, and selected agencies. (KC)

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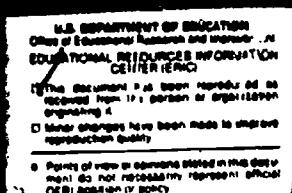
REHABILITATION NEEDS ASSESSMENT  
FOR  
VOCATIONAL REHABILITATION AGENCIES

VOLUME II

Needs Assessment Topics  
Identified in the Rehabilitation Act:  
Issues and Resources

by

*The Region V Study Group*



CE 059 667

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**REHABILITATION NEEDS ASSESSMENT  
FOR  
VOCATIONAL REHABILITATION AGENCIES**

**VOLUME II:**

**Needs Assessment Topics  
Identified in the Rehabilitation Act:  
Issues and Resources**

*by*

*The Region V Study Group*

*March, 1991*

*With Participation of*

**The Research and Training Center  
University of Wisconsin-Stout**

**Rehabilitation Continuing Education Program  
Southern Illinois University**

**Region V Regional Office at Chicago  
Rehabilitation Services Administration**

## *Preface*

The Region V Study Group is composed of individuals on staff at state rehabilitation agencies in the region. The Research and Training Center at the University of Wisconsin-Stout (RTC), the Rehabilitation Continuing Education Program (RCEP) at Southern Illinois University, and the Regional Office of the Rehabilitation Services Administration at Chicago (RSA) provided consultation, facilitation, technical support, and publication resources to the Study Group. Rehabilitation Needs Assessment for Vocational Rehabilitation Agencies is the second project completed by the Region V Study Group. The concept, development, direction, and product, however, are those of the staff of the state agencies.

This project began after completion of the "Gender Study."<sup>1</sup> A series of project concepts was identified by Region V program evaluation staff at their Annual Meeting at Madison, Wisconsin, in October, 1987. Four concept papers were prepared and presented to the Region V Council of State Administrators of Vocational Rehabilitation at their winter meeting. The "needs assessment" issue was given highest priority as most state agencies were searching for methodologies with which to meet the expanded requirements in the 1986 amendments to the Vocational Rehabilitation Act that the state plan be based upon a "comprehensive needs assessment." The council anticipated that a guide, tool kit, or state-of-the-art document that was developed from current legislative requirements by and for agency personnel would be of greatest benefit to state agencies.

Each state agency selected members for the Study Group and the Group met in January, 1988, to review the charge; develop a working timeline; establish commitments from the RTC, RCEP and RSA; and prepare a working budget for the Council's response and support. The first meeting in May produced a working concept of rehabilitation needs assessment that incorporated rehabilitation legislation requirements, developed a general outline for the guide, identified specific research and writing assignments for the Study Group, and clarified the goals and purposes for the project.

The identified goal of the Study Group's project was to produce a document which would put needs assessment within the contexts of providing rehabilitation based on identified consumer needs, preparing the State Plan for Vocational Rehabilitation, and meeting state and federal requirements. The purposes of the project were broadly conceived as follows:

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<sup>1</sup>The first project was a formal research study to determine how women fared in the vocational rehabilitation process. Region V Study of Access, Services and Benefits from Vocational Rehabilitation 1972 to 1984: A Gender Perspective was completed and published by the Research and Training Center at the University of Wisconsin-Stout in September 1987.

- Develop a practical guide for conducting needs assessment in rehabilitation.
- Develop simple methods for conducting needs assessment studies.
- Develop cost-effective methods for conducting needs assessment studies.
- Identify additional and useful information sources and resources with which to conduct needs assessment studies.
- Describe the application of needs assessment methodologies to specific problems in planning.
- Develop improved models of needs assessment for improving decision making, including providing accurate technical assistance data and proactive information on emerging issues.
- Develop general methodologies or conceptual models for the various types of needs assessments.
- Clarify fundamental needs assessment issues.
- Improve the availability of information to support decision making.
- Establish an ongoing resource for state agencies to conduct needs assessments.
- Develop needs assessment methods that will assure that state agencies will obtain needs data of a quality they can rely upon.
- Promote comparability among state needs assessment studies.

The outcome of the project was to be a document that would both provide appropriate technical information for planning and conducting rehabilitation needs assessment and provide guidance on how to effectively perceive and apply rehabilitation needs assessment findings to rehabilitation planning and delivery.

Subsequent meetings held periodically during 1988 combined training in the principles of needs assessment and work on the developing document. Materials prepared by the Study Group, in keeping with their assignments, were the bases for both the training and the work sessions. Training attended to developing basic concepts and studying the legislative history behind the requirements for comprehensive needs assessment found in amendments to the Rehabilitation Act. The work sessions concentrated on critical review of materials submitted by writers and on revision, integration, and improvement of the structure and focus

of the proposed document.

Following the October 1988 meeting, an editorial committee was formed to integrate all materials and determine final segments of the document that needed to be solicited from the Study Group. The editorial committee met in March; new assignments were made, and all final materials were reviewed and integrated by between May and July, 1989. In October, 1989, the full Study Group convened at the 10th Annual Meeting of Region V Program Evaluators, at Chicago, for further considerations before the document was submitted for review by the Region V state administrators. Final editing took place in fall, 1990. The Study Group's product was presented to the winter meeting of the Region V Council of State Administrators of Vocational Rehabilitation.

**The Editors:**

**Fredrick Menz, RTC, Wisconsin,  
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**March 1991**

## *Acknowledgements*

We wish to acknowledge the many individuals and organizations involved in the preparation of this document. First, our appreciation goes to the state directors of vocational rehabilitation for their foresight, for their willingness to allow this to be part of staff responsibilities, and for the resources they allocated to development of this inter-state product. We must acknowledge the help of Dr. Henry Wong of the RCEP for his contributions and for coordinating arrangements and meeting sites for Study Group and editorial committee meetings. We thank Dr. George McCrowey of the Chicago Regional Office of the Rehabilitation Services Administration for his continuing participation, contributions, and guidance throughout the project.

We wish to acknowledge Drs. Fredrick Menz and Daniel McAlees of the Research and Training Center for their continuing involvement in helping the Study Group embark on this book writing task and not letting the Group stop until they had finished the product. Thanks also to them for effectively facilitating the Study Group's growth in their understanding of needs assessment from "doing a survey" to the conceptualization of needs assessment as the cornerstone for rehabilitation planning that we present throughout this book and for securing funds to publish and disseminate this document. We thank Dr. Frank Corrigan, Acting Commissioner, Rehabilitation Services Administration, for his insightful presentation at the 9th Annual Program Evaluation Conference and the paper he subsequently prepared on the evolution of needs assessment under the Rehabilitation Act. We thank the U.S. Department of Education's Rehabilitation Services Administration and National Institute on Disability and Rehabilitation Research for the partial funding that made this document possible. A very special appreciation goes to Ms. Julie Larson at the Research and Training Center who guided the scripting, preparation, and printing of this document through all of its rough and final phases.

Special commendation goes to a particularly important Study Group colleague: Dr. Robert Struthers, who retired as Director of Program Evaluation, Michigan Rehabilitation Services, in 1989 and left the Study Group. Dr. Struthers has been and continues to be the true inspiration behind the development of documents like this by state agency personnel. While it is more often academics who can assume leadership in a profession, Dr. Struthers has demonstrated that those of us engaged as functional evaluators and planners can also have an impact on our profession beyond the boundary of our state agency. Bob has been the single most identified person in state agency program evaluation for the past 15 years. To those of us attempting to document and improve our state's rehabilitation programs, Bob's name, publications, and ideas are considered synonymous to Quality. His competence and leadership have made it possible for many of us to look beyond the confines of our daily responsibilities to the possibility of what and how we relate to each other as professionals and how our collective skills can be enriched and do enrich our profession. His gentle reach continues to help us bridge those gaps and has

helped us immeasurably to produce a document with quality. He continues to help us realize that where we are now is but one step to what we will be able to do tomorrow.

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## *Chapter 1*

### **Overview of the Volume**

Volume I provided background information on contemporary needs assessment approaches and the Region V Study Group's concept and methodology for carrying out comprehensive rehabilitation needs assessment. That volume (a) examined the issues that constrain the rehabilitation program and the needs assessment and planning processes; (b) related how comprehensive needs assessment became a requirement in the 1986 Amendments to the Rehabilitation Act and how that requirement affects State Plan development; (c) reviewed and contrasted contemporary needs assessment definitions, models, and techniques for what they have to offer to agency planning; (d) offered practical advice on what needs assessment information and requirements mean for the agency that contemplates "a comprehensive needs assessment"; and (e) presented a concept and step-by-step methodology.

Volume II provides state agency personnel with tools for conducting rehabilitation needs assessment. The volume provides practical guidance and resources for conducting special needs studies. As the readers consider the need for special assessment studies, their selection of design and assessment technology should proceed only after they have carefully considered the following: (a) Requirements and meaning of the legislative mandates for services at both the state and federal levels; (b) definition of the target population or program; (c) an examination of vocational rehabilitation program structure in relation to the total state service delivery system; (d) past management decisions for resource allocation relevant to program delivery; (e) availability and quality of current information on needs; and (f) the agency's purpose, intended utilization, and resources for conducting a needs assessment effort.

This volume offers concrete suggestions and specific resources that state agency personnel can use to develop statewide and special needs assessment studies. Used together, the chapters and appendices can help agency personnel obtain a broader understanding of populations and services and how special characteristics of each can be interfaced to develop a comprehensive statewide needs assessment methodology. The chapters and appendices to the volume, however, were written so that they might be used separately or collectively to design an assessment. Certain key material is intentionally repeated from chapter to chapter. Each chapter can be photocopied and used separately to guide the agency's development of a targeted needs assessment effort.

**Chapter 2.** Chapter 2 provides a summary of the Region V Study Group's concept of comprehensive needs assessment.<sup>1</sup> That chapter begins with a brief restatement of the Group's definition of comprehensive needs assessment and how it fits into program planning. Basic assumptions about needs assessment and program planning in rehabilitation are then summarized, followed by an overview of the Study Group's point of view, concept, and needs assessment model. The chapter concludes by presenting the case for special needs assessment studies as part of the agency's comprehensive needs assessment.

**Chapter 3.** This chapter provides a careful analysis of federal regulations for assessment and evaluation. It should be reviewed before specific needs assessment studies are designed and as results of the assessment are being used in program planning and preparation of the State Plan.

**Chapters 4 through 18.** The populations discussed in this volume are ones specified in the rehabilitation legislation and ones that Region V agencies are finding are underserved or increasingly applying for rehabilitation services. These emerging populations can make unexpected demands on present rehabilitation resources. The impact of their disabilities and cultural differences may require unique rehabilitation services and, consequently, make unique demands on the rehabilitation program and its planning. The services discussed are those identified in rehabilitation legislation. Among the services and populations discussed in this volume, those followed by an \* are specifically identified in regulations and the Rehabilitation Act:

### Needs of Specific Populations

- Chapter 4. Individuals with Severe Handicaps\*
- Chapter 5. Chronic Mental Illness\*
- Chapter 6. Developmental Disabilities
- Chapter 7. Specific Learning Disabilities
- Chapter 8. Traumatically Brain Injured
- Chapter 9. Blindness and Visual Impairments\*
- Chapter 10. Deafness\*
- Chapter 11. Youth in Transition\*
- Chapter 12. Minorities and Underserved Populations
- Chapter 13. Native Americans\*
- Chapter 14. Women

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<sup>1</sup> The reader is encouraged to read Volume I for a complete discussion of the Study Group's methodology for conceiving, designing, carrying through, and utilizing assessment findings in program planning and redevelopment.

## **Need for Designated Services**

- Chapter 15. Rehabilitation Facilities\***
- Chapter 16. Supported Employment\***
- Chapter 17. Independent Living\***
- Chapter 18. Rehabilitation Engineering\***

Chapters 4 through 18 are really at the heart of the special studies concerns in this volume. Chapter 4 should be read in conjunction with the other more disability and service specific chapters. Chapter 4 (a) focuses on general issues to be aware of in assessing needs of persons with disabilities or who have culturally different background; (b) illuminates some of the general practical and ethical cautions in constructing instruments and collecting valid needs data; (c) discusses a variety of sources for needs data and where assistance may be obtained to conduct needs studies; and (d) provides selective lists of federal, private, and bibliographic resources.

Chapters 5 through 18 each covers a single assessment topic and provides the following: (a) Discussion of the population or service and problems one might encounter when assessing need; (b) summary of the related federal requirements or authority, when appropriate; (c) discussion of special considerations for conducting assessment of needs for the population or program; and (d) selective listings of agencies and organizations, research centers and projects, bibliography, and other resources that are available and may provide needs data or assistance in designing, conducting, and using findings from needs assessments.

**Appendices.** The appendices to the volume are actually a compendium of specific resources and lists (many of which were included in parts of the chapters). The first four appendices include an extensive bibliography, a short list of selected technical references, a suggested format for a needs assessment report, and the addresses and locations of clearing-houses and common secondary data sources. The next several appendices identify resources that will be useful sources of information or assistance in designing and using needs information. The address and phone number of a contact person are provided for current Research and Training Centers, special spinal cord and traumatic brain injury centers, Rehabilitation Engineering Centers, Regional Continuing Education Programs, and sources for information on University Affiliated Programs, and Veterans Administration research centers. The last two appendices provide addresses and phone numbers for selected federal agencies, regional offices, and consumer and advocacy organizations.

## *Chapter 2*

# **A Summary of the Region V Rehabilitation Needs Assessment Concept**

Who to serve, what resources are needed to serve them, where should services be located, how much will adequate coverage cost, and whose needs will agency programs not be able to meet? These are all questions for which agency decision makers and planners must have answers. Variations of these questions are the fundamental questions that rehabilitation needs assessment is expected to address.

In this chapter the Region V Study Group's concept of comprehensive needs assessment is briefly summarized.<sup>1</sup> The volume provides practical guidance and resources for conducting special needs studies. This chapter begins with a brief restatement of the Group's definition of comprehensive needs assessment and how it fits into program planning. Basic assumptions about needs assessment and program planning in rehabilitation are then summarized, followed by an overview of the Study Group's point of view, concept, and needs assessment model. The chapter concludes with a presentation of the case for special studies as part of the agency's comprehensive needs assessment.

### **Comprehensive Needs Assessment**

*Needs assessment is a continuing process for systematically gathering and synthesizing valid information on the needs of individuals that is relevant to the planning and development of vocational rehabilitation service delivery programs. Needs assessment is a proactive, intentional activity. Although incidental and casual sources of data may influence planning, needs assessment is carried out on an ongoing basis, in a systematic manner, as an integral part of the agency's planning function.*

In this definition, comprehensiveness implies that assessment is a dynamic function integral to the program's ongoing cycle of planning and evaluation. It is not synonymous with a large scale, single point-in-time gathering of information. Depending on the issue stimulating a particular needs assessment effort, the scale and sources of data used to assess needs may be large or small, broadly or selectively acquired. For example, a planning issue requiring statewide incidence estimates of persons with handicapping conditions would require large scale data collection efforts. On the other hand, an assessment

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<sup>1</sup> The reader is encouraged to read Volume I for a complete discussion of the Study Group's methodology for conceiving, designing, carrying through, and utilizing assessment findings in program planning and redevelopment.

driven by an issue of needing to plan for the rehabilitation needs of Southeast Asian refugees would require a smaller scale and more specialized effort. Both examples comprise instances of assessments that are part of a comprehensive assessment process. Neither example, in and of itself, is an inclusive example of comprehensive needs assessment.

The process for planning and conducting the assessment presented in this chapter, however, can help the agency achieve the intended goals for needs assessment both in rehabilitation legislation and, historically, in agency planning.

Comprehensive needs assessment provides answers and direction to today's planning and allocation issues and provides guidance in planning for the future structure and resource requirements of the state's rehabilitation program. No single technique or model of needs assessment for state vocational rehabilitation programs is proposed by the Region V Study Group. The general management and planning issues an assessment will address are likely to be quite similar among states. The specific method appropriate in a particular state will, however, depend on the unique features and composition of the state, the particular resources the agency can avail for planning and delivering rehabilitation services, and the state specific issues that will drive the current assessment activity.

The state's comprehensive needs assessment model should be developed within the context of that state's service delivery and be incorporated into the agency's mission, values, and objectives. Each agency's assessment and planning effort must consider the overall habilitation and rehabilitation infrastructure in the state. The model must account for the social, political, and economic realities of the state that will influence the agency's capacity to plan based on needs assessment information and how other state, county, and local agencies play important parts in meeting rehabilitation and habilitation needs of the state's disabled population. Needs assessment tools have to be crafted by each vocational rehabilitation agency program consistent with its capability for systematic planning and development.

### **Assumptions About How Needs Assessment Can Influence Program Planning**

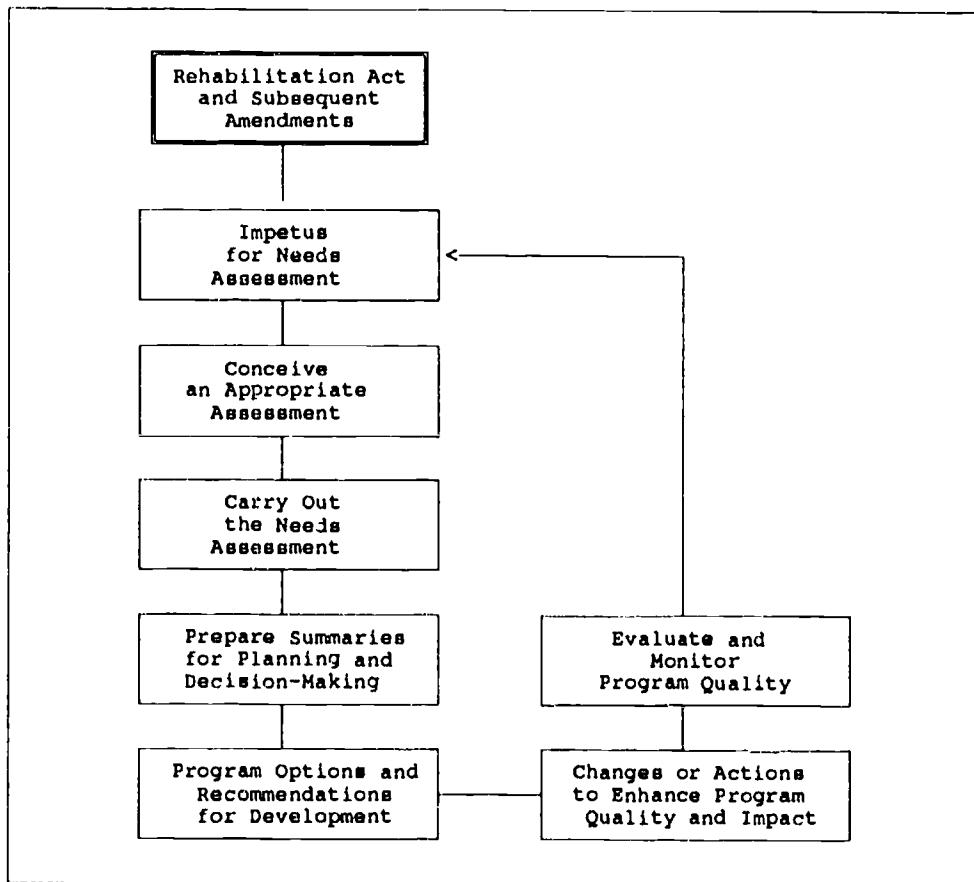
The fundamental assumption behind the above definition and the Region V conceptualization of needs assessment is that what the state agency does and how the agency approaches its rehabilitation mission can be influenced by the findings and recommendations from its needs assessments. As conceived, rehabilitation needs assessment is expected to lead to changes in state agency goals, objectives, and use of resources. However, it is important to realize that the extent to which specific needs assessment activities will be used in planning and decision making is related to how well the following assumptions are understood by those conceiving the assessment:

- Program planning and development take place in a socio-economic-political context. Restricted perceptions of socio-economic opportunities and conditions and consumer, professional, and public pressures influence how and which rehabilitation goals are selected and, as a result, influence how rehabilitation resources are deployed.
- Program development remains dynamic as long as political, economic, and social pressures are extant. The evolution and use of needs assessment will become influenced by these pressures and the political process in which rehabilitation planning takes place.
- Needs assessment is a formal methodology that follows accepted conventions for accessing, collecting, compiling, and synthesizing information relevant to program decisions. Systematic procedures are adhered to. Each step can be replicated. Results can be verified. Conclusions and recommendations can be logically and empirically related to the assessment results.
- No single set of information, no matter how systematically planned and collected, will be sufficient, in and of itself, to direct all program planning.
- Multiple sources of information (including both informal data and formally obtained assessment data) will be used by planners and administrators in setting priorities for services in a dynamic rehabilitation system.
- Needs assessment can influence decision making only to the extent that it is conceived and conducted to have contextual validity and provides information and options more compelling to decision makers than other sources of information.
- Needs assessment must acquire accurate information on questions and issues relevant in the political decision-making process, must clearly present findings, and must offer recommendations which are compelling to the end-user.

### **A Conceptual Structure for Rehabilitation Needs Assessments**

The Region V Study Group's concept of needs assessment is that of a model in which the assessment process is cyclic and integral to program planning and development. As portrayed in Figure 1, the Study Group argues that the intent of rehabilitation legislation was not that agencies conduct a single study. Rather, the legislation intended that needs assessment would effectively tie planning,

budgeting, program delivery, and program evaluation together. Comprehensiveness, therefore, complements the pervasive idea of "integrated program design and delivery" inherent in the state-federal rehabilitation program.



**Figure 1. Region V Conceptualization of Rehabilitation Needs Assessment**

### Stimulus for Needs Assessment

Different stimuli will prompt initiation of a planning cycle for the entire program or for a very small part of the program. In Figure 1, the importance of the Rehabilitation Act to the state rehabilitation program is shown as the initial stimulus for conceiving and developing a state program based on consumer needs: The 1986 requirement "that a comprehensive needs assessment be conducted" and that the "state plan include its response to its needs assessment."

This kind of "mandated" stimulus is the most dramatic and will likely lead many states to conduct a very broad-based assessment of needs in the state. The figure also suggests that the Act is the referent for subsequent reappraisals. As

requirements for the state program are altered (e.g., new federal initiatives are pursued), as public expectations change (e.g., by a more informed consumer), and as population needs change (e.g., emergence of immigrants), the agency will be required to consider whether and how the state rehabilitation program must be redeveloped.

Stimuli for initiating subsequent specific assessment effort and planning cycles may come from several sources. Technological-scientific progress, socio-economic changes, and public pressure are among the most likely to prompt a possible shift in program focus. Technological-scientific progress includes improved methods and technology that allow more persons to overcome impairments brought on by a disability and to benefit from rehabilitation processes (e.g., treatment of head injuries has increased the likelihood of post-injury survival). Socio-economic changes include attitudinal or economic changes that affect individuals' potential for access to work opportunities by persons with disabilities (e.g., labor shortages in entry-level service jobs). Public pressure, above all else, provided in part by advocates and disabled persons themselves, can stimulate change. It can promote evolution of the Act and public policy or direct demands on the state program (e.g., passage of the American's with Disabilities Act).

Other stimuli that can set an assessment-planning cycle in motion include (a) negative findings from a program evaluation, (b) unusual declines in referrals from a target source, (c) internal changes in program staffing that require staff development, (d) budget cuts by the legislature, (e) judicial decisions affecting eligibility and closure criteria, (f) changes in state labor laws, (g) public demands for specific changes, and (h) staff-identified issues and proposals.

### Conceiving an Appropriate Needs Assessment

Unfortunate though it might be, rehabilitation services are planned on the basis of partial information, a condition that the needs assessment effort should attempt to alleviate. When conceiving the design of the assessment, decision makers and planners should be involved in (a) identifying the issues which are most important to decision making, (b) exploring how the findings and recommendations from the assessment can be used, and (c) deciding how much of the agency's resources (time and effort) can be invested in acquiring usable needs data and in managing the change process once new needs are identified.

Needs assessment should be designed to provide the information that is most required for agency decision making and planning. It is more likely that results will be acted upon if their use in program planning is considered well in advance of instrument selection and data collection. The level of agency investment in needs assessment (and using it in planning) will vary given the importance of the stimulus issues. In general, it is of little benefit to generate more data than the system is able to use or able to plan with. Likewise, it is not

worthwhile to generate data about issues that are only incidental to the planning and decision making that will come about. Similarly, the design for the assessment should be in keeping with the agency's resources to acquire, organize, and report needs information and the agency's resources to conduct systematic data-based planning (e.g., prepare and act upon program options and recommendations).

Similar decisions are made at the federal, state, and local levels. Federal decisions require valid national data, state decisions require representative state data, and local decisions require valid data about need and issues that will affect effective planning. Likewise, various sub-programs in the agency will require needs data for certain sub-populations that may be defined by disability type, age level, expected outcomes of services, and other variables. Regardless of the administrative unit or level of government, the following are the general types of decisions to which assessment findings are expected to make valid contributions:

- What specific rehabilitation programs there should be.
- How large the specific program service needs to be.
- What specific services and resources should be provided.
- What resources, skills, and capacities need to be developed to provide the services.
- What additional needs information should be obtained.

Federal legislation requires statewide planning for vocational rehabilitation. While the focus is on the vocational rehabilitation program, similar functions are performed for independent living, supported employment, and other designated programs. The primary decisions about the types and sizes of programs are made at the executive level in most state rehabilitation agencies. Decisions about program models and their geographic distribution may be made by program managers. Decisions about local programs and services to individual clients are made by local managers and counselors. While information is needed at all program levels and locations, the level at which planning data are presumably first needed is at the state level, where the most far-reaching agency decisions are made.

Selection of specific methods to collect relevant information should follow once consensus is achieved on the issues and focus for the assessment, potential uses of the findings in planning, and the level and types of resources that will be available for conducting and using needs assessment findings. A written needs assessment design should specify the (a) issues upon which the study will

focus; (b) specific data that will be accessed relative to those issues; (c) data sources or populations from whom data would be acquired; (d) method for sampling data or a population (if necessary); (e) instrumentation and procedures for collecting or recording data; (f) procedures for validation of data and protection of participants; (g) data processing and analysis; (h) prospective reporting formats and data processing needs; and (h) operational plan, including major activities, individual responsibilities, timelines, and budget.

### **Carrying Out the Needs Assessment**

The selection of a methodology is guided by issues of data quality, by efficiency in the use of agency resources, and by staff sensitivity to the political context within which information from needs assessment will be used. It is at this point that agency personnel directing the assessment activity must be most rigorous in use of their technical skills. Whether the assessment is conducted internally or under contract, the responsibility for assuring that the approach used to appraise needs is of acceptable professional standards and of practical use must remain in the hands of agency staff responsible for the study.

Plans for how needs assessment information will be used in planning and procedures for verification should be developed at the same time the assessment approach is selected and before the method is implemented. Quality control must be introduced, whether the assessment method is a systematic application of a research principle (e.g., by imbedding validating questions in an interview protocol, by checking sample parameters against the original sample plan) or is a secondary analysis of existing data from reports (e.g., by cross-verifying assumptions for extrapolating estimates, by independently recoding content from open-ended questions).

### **Using Needs Assessment to Influence Program**

The needs assessment findings are most useful when they respond concisely to the decision making issues that were originally identified and when practical interpretations and options relevant to the planning process are presented. No data are inherently worthwhile, useful, or valid in application. Interpretation of the findings prepared jointly by the several interested parties (i.e., decision makers, planners, and the assessment staff) can help assure that the results of the assessment are adequately related to the planning process.

Often the technical assessment process is considered complete when the findings are presented to the administrator. The use of the assessment results, however, is a part of the larger planning process that will not only consider identified needs and resources but also competition for resources. Existing system commitments and the capacity of the system to address any needs place limits on what can and will be implemented.

Need-based planning is, therefore, much more than the application of findings. The values of all persons concerned with the rehabilitation program (advocates, administrators, practitioners, politicians, and the general public) do become involved. Decisions about how to deploy (or redeploy) resources, how to change ways in which services are made available, and how to fit novel approaches into the system are affected by agency staff values and the broader socio-economic-political context of the program. The role of the assessment team at this point in the planning process is in helping the agency to remain responsive to the significant needs identified in the assessment.

### **Continuing the Comprehensive Cycle**

The process, as described, continues because the fundamental issues continue to reappear and must be re-addressed. Not all significant changes in the program required by federal mandate or identified as an assessed need will occur at once. Needs assessment and planning do not produce a completely formed "new" system. Unmet needs and new stimuli will reinitiate this planning process.

Systems as complex and established as is a state rehabilitation program usually change in incremental steps. As such, the utility of the assessment may not be fully realized in the initial cycle but may become a continuing source of information and guidance to the program planning process. With each cycle, assessment information accumulates; and an increasingly complete picture develops of what is, what is needed, and what can be accomplished with the agency's resources. Program planning is, then, increasingly able to help the agency meet consumer needs as administrators and planners come to differentiate what has been and what has yet to be accomplished.

### **Requirements for the State Rehabilitation Agency**

This conceptualization of needs assessment as an integral part of agency planning and development makes certain demands on vocational rehabilitation programs. It requires that state agencies:

- Commit to using needs assessment findings in program planning and decision making;
- Establish policies based on concerns for equity of services;
- Establish performance standards for program and services based on population proportions, disability prevalence rates, and other factors relating to order of selection or other service priority mechanisms; and
- Maintain a monitoring system sensitive to assessing agency

performance in serving various population segments.

### **Qualities of a Useful Rehabilitation Needs Assessment**

As depicted in the Region V concept, needs assessment has a central role in the agency's continuing process of redirection, redeployment, or redevelopment of the program. Such functionally valued guidance results from a well conceived and conducted assessment. The following are the qualities of such an assessment:

- **Consciously designed.** Design of the assessment was conceived around and developed to address the issues most important for planning and management of a responsible rehabilitation program.
- **Contextually relevant.** Designs and procedures were adopted that sensitively anticipate and account for the pressures and influences that can bias the assessment and adversely affect decision making and delivery of a program that meets important rehabilitation needs.
- **Properly conducted.** Appropriate sources of data and techniques to acquire data were used that efficiently provide measurements relevant to the management issues and to subsequent planning and decision making.
- **Meaningfully compiled.** Assessment data were accurately synthesized and the results translated to identify compelling information and specific options and program recommendations.
- **Effectively communicated.** Findings and recommendations were presented to planners and decision makers in formats and in language meaningful to their roles. Options and recommendations were presented accurately, clearly, and concisely while sensitive to pressures and influences that may constrain implementation of options.

### **The Case for Special Studies of the Expanded Rehabilitation Population**

The Rehabilitation Act of 1973, subsequent amendments, and resulting regulations require state vocational rehabilitation agencies to "determine the relative needs of handicapped individuals, with special reference to the need for expanding services to individuals with the most severe handicaps." The needs of most groups can be determined through general needs assessment approaches

that take into consideration the characteristics of various population segments in their design. Studies that more finely examine needs specific to these groups are also required under a comprehensive assessment approach.

The necessity for these studies is driven by agency responsibility to maintain equity in service delivery among the various population segments. Special studies are called for when a particular population or service segment is (a) targeted in the Rehabilitation Act, (b) underrepresented, (c) not receiving comparable services, or (d) not achieving comparable outcomes. This volume focuses on how state agencies can conduct special studies as part of their comprehensive assessment and planning to be in compliance with the federal regulations.

As the reader notes, the Region V Study Group's concept does not limit special studies to those specific populations and services identified in various sections of the law and regulations. Rather, it is the Study Group's contention that agencies must be increasingly aware of and anticipate how the unique needs of other segments of America's disability population can be served. Special studies may require both an assessment of needs of the targeted populations and of current agency practices related to these populations. These studies include consideration of the disability prevalence rates and the sensitive indicators of rehabilitation-related needs; quality, impact, and satisfaction. They will likely examine social and environmental issues, organizational issues, and individual characteristics in order to identify unique needs and address how the rehabilitation process might appropriately address needs. The assessment will also seek out those rehabilitation processes that must change to achieve more equitable services and outcomes for the targeted group.

## *Chapter 3*

# **State Plan Requirements for Needs Assessment and Program Evaluation**

The amended Rehabilitation Act of 1973 (a) establishes state authorities and responsibilities for providing rehabilitation programs, (b) enables state rehabilitation agencies to plan and use their resources to meet the needs of targeted groups of persons with disabilities, and (c) requires state agencies to use as a basis for the planning and delivery of services a comprehensive assessment of needs. Amendments to rehabilitation legislation have historically made specific reference to the segments of America's population who are to be given priority for delivery of services. In recent years, the forms for the delivery of services, use of rehabilitation facilities, provisions for independent living services, use of supported employment programs and services, and application of rehabilitation engineering services have also been indicated. These legislative requirements and authorities cause rehabilitation program managers to address critical management issues and stimulate intensive program planning. Issues to be addressed during intensive program planning include the following:

- Who will be given greater priority for services and resources.
- What existing or new services and resources are required.
- How to allocate or redeploy existing resources.
- How to identify and acquire new and/or presently unavailable resources.
- How to maintain program quality as shifts in program emphasis or priority populations occur.

The attention and responses state agencies make to these basic management issues establish parameters for program planning and development. State rehabilitation agencies tend to perceive needs assessment as a specific and discrete activity that starts with a prevalence or incidence study of the state's population of disabled individuals. The results of this activity are often submitted to the Rehabilitation Services Administration as a required attachment to the State Plan and, in some cases, placed in a state agency file and not looked at until there is again that specific need to report to the federal government. Consequently, this needs assessment does not reflect the integral part that comprehensive needs assessment is supposed to play in a continuing program planning, development, monitoring, and evaluation cycle.

As the authors have stressed throughout Volume I, a quality needs assessment should do more than satisfy a basic State Plan requirement for comprehensive needs assessment. Assessment studies provide valuable

information needed by administrators and managers of vocational rehabilitation agencies. Comprehensive needs assessment, as posed in legislation and required by regulations, is a way to integrate program planning, development, budgeting, and monitoring and is the foundation for evaluation and re-evaluation of new and old rehabilitation programs and services. It should include a summary of the results of a statewide assessment of the rehabilitation needs of individuals with handicaps in the state; a report of the state agency's review of the variety of methods and procedures for providing, expanding, and improving services to persons with disabilities; and a description of how it will determine which of these methods and procedures are the most effective. (See 34 CFR 361.17 (b).)

Federal requirements for rehabilitation needs assessment can be translated into a series of Vocational Rehabilitation Agency State Plan items and issues. The remainder of this chapter carefully analyses and summarizes these needs assessment and evaluation items and issues that should be considered by program managers and evaluators. This analysis was prepared by Dr. George McCrowey and staff from the Rehabilitation Services Administration Regional Office at Chicago, Illinois, specifically for this text. Items are organized in accord with the State Plan sections under which each is officially listed in the federal Rehabilitation Act and the regulations adopted by the state Rehabilitation Services Administration. Appropriate citations identifying the federal legislative and regulatory requirements are in corresponding citation notes at the end of the chapter.

### **State Plan Requirements Section 110, the Basic State Program**

#### **Staffing<sup>1</sup>**

State agencies should have staff in sufficient numbers and with appropriate qualifications to carry out all functions required under the Act and 34 CFR 361.14. Required functions include program planning and evaluation, staff development, rehabilitation facility development and utilization, medical consultation, and rehabilitation counseling services for severely handicapped individuals. Issues related to staffing include

1. What is the number of staff in the state unit?
2. What is the number of counseling staff in the state unit?
3. What is the number of support staff in the state unit?
4. What is the average client/counselor ratio?
5. What is the staff turnover rate for the state unit?

6. Are staff equitably distributed and in sufficient numbers to assure quality and timely services to state unit clients and to persons referred for rehabilitation services?
7. Are qualified staff available to carry out all functions required under the Act and 34 CFR 361.14 (e.g., program planning and evaluation, staff development, rehabilitation facility development and utilization, medical consultation and rehabilitation counseling services for severely handicapped individuals)?
8. What is the number of administrative staff in the state unit?

### **Staff Development<sup>2</sup>**

State agencies are expected to assure that there is a program of staff development for all classes of positions that are involved in the administration and operation of the state vocational rehabilitation program in accordance with 34 CFR 361.16. The staff development program must include, as a minimum, (a) a systematic determination of training needs to improve staff effectiveness and a system for evaluating the effectiveness of the training activity provided, (b) an orientation program for new staff, and (c) an operating plan for providing training opportunities for all classes of positions consistent with the determination of training needs. The issues are

1. What is the system used to determine training needs to improve staff effectiveness?
2. Are results of case reviews and evaluation studies used to determine training needs?
3. What is the system used to evaluate the effectiveness of training activity?
4. How are needs assessment data and other information used to identify new and/or different staff training needs?

### **Utilization of Rehabilitation Facilities<sup>3</sup>**

The state unit can, if appropriate, enter into agreements with operators of facilities that provide services to eligible handicapped individuals. The State Plan should describe the methods used to ensure appropriate use of facilities and must provide appropriate means for entering into agreements with operators of facilities that provide rehabilitation services. The State Plan must assure that the state unit utilizes existing rehabilitation facilities to the maximum extent feasible to provide vocational rehabilitation services to handicapped individuals in accordance with the State Plan for Rehabilitation Facilities. The issues include

1. Are service agreements with facilities based on need?
2. How is the need to develop a service agreement with a facility determined?
3. What is the current state unit rehabilitation facility use rate?
4. Are existing rehabilitation facilities able to adequately provide the type, quality, and quantity of services needed by state unit clients?
5. What are the most cost-effective means for acquiring needed facility services?
6. Are existing rehabilitation facility services geographically located so that rehabilitation services are reasonably accessible to clients across the state?

### **Services to American Indians Who Are Handicapped<sup>4</sup>**

The designated state unit should provide vocational rehabilitation services specified in Section 6.1 (a) of the state plan to handicapped American Indians residing in the state to the same extent that such services are provided to other significant groups of the state's handicapped population.

The State Plan must further assure that the designated state unit continues to provide vocational rehabilitation services to handicapped American Indians on reservations served by a special tribal program under Section 130 of the Rehabilitation Act (i.e., Vocational Rehabilitation Services Grants for American Indians Located on Federal or State Reservations). Specific issues include

1. What is the American Indian population of the state?
2. Does the state unit have a method for assessing the rehabilitation services needs of the state's population of American Indians?
3. How are information and/or data on American Indian rehabilitation services needs used to plan and develop rehabilitation programs and services?
4. How often does the state unit plan to assess the needs of its American Indian population?

### **Construction of Rehabilitation Facilities<sup>5</sup>**

If the designated state unit is to provide for the construction of public or other nonprofit rehabilitation facilities, then the state unit (a) carries out this activity in conformity with its State Plan for Rehabilitation Facilities, (b) determines that there is a need for the construction of a rehabilitation facility,

and (c) assures that the construction of a facility is in accord with requirements in 34 CFR 361.1 (c) and 34 CFR 361.52. The specific issues are

1. What is the method used by the state unit to determine the need to construct rehabilitation facilities?
2. How does the state unit assure that there is a need to construct a rehabilitation facility?

### **Establishment of Rehabilitation Facilities<sup>6</sup>**

If the designated state unit is to provide for the establishment of public or other nonprofit rehabilitation facilities, then the state unit (a) carries out this activity in conformity with its State Plan for Rehabilitation Facilities and (b) determines that there is a need for the establishment of rehabilitation facilities. The specific issues are

1. What is the method used by the state unit to determine the need to establish a rehabilitation facility?
2. How does the state unit assure that there is a need to establish a rehabilitation facility?

### **Continuing Statewide Studies and Program Evaluation**

#### **Statewide Studies<sup>7</sup>**

The designated state unit should conduct continuing statewide studies of the needs of handicapped individuals within the state, the state's need for rehabilitation facilities, and the methods by which these needs may be most effectively met. Such studies should address the purposes specified in 34 CFR 361.17 (b) and include the following issues:

1. What is the method used to determine the relative need for vocational rehabilitation services by different significant segments of the population of handicapped individuals, including utilizing data provided by state special education agencies under 618 (b) (3) of the Education of the Handicapped Act, with special reference to the need for expanded services to individuals with the most severe handicaps.
  - (a) How are continuing statewide studies of the needs of handicapped individuals conducted?
  - (b) When was the last statewide study of the needs of handicapped individuals conducted?

- (c) What were the results?
- (d) Did this study cause changes in state agency policy, procedures, and/or programs?
- (e) When is a follow-up study scheduled?

2. What method or procedure does the state unit use to review a broad variety of methods and procedures to provide, expand, and improve vocational rehabilitation services in order to determine which means and methods are the most effective?

- (a) How does the state unit review a broad variety of means and methods for providing, expanding, and improving vocational rehabilitation services?
- (b) When was the last study of methods and procedures for providing, expanding, and improving vocational rehabilitation services conducted?
- (c) What were the results?
- (d) Did this study cause changes in state agency policy, procedures, and/or programs?
- (e) When is a follow-up study scheduled?

3. What method or procedure does the state unit use to review the appropriateness of the criteria used by the state unit in determining individuals to be ineligible for vocational rehabilitation services?

- (a) How does the state unit review the appropriateness of the criteria used to determine whether individuals are ineligible for vocational rehabilitation services?
- (b) When was the last study to review the appropriateness of the criteria used to determine individuals to be ineligible for vocational rehabilitation services conducted?
- (c) What were the results?
- (d) Did the results of this study cause changes in state agency policy, procedures, and/or programs?
- (e) When is a follow-up study scheduled?

4. What method or procedure does the state unit use to determine the capacity and condition of rehabilitation facility services within the state and use to identify ways in which the overall effectiveness of rehabilitation facility services within the state may be improved?
  - (a) How does the state unit determine the capacity and condition of rehabilitation facility services within the state and how does the state unit determine the overall effectiveness of rehabilitation facility services?
  - (b) When was the last study to determine the capacity and condition of rehabilitation facility services and the overall effectiveness of rehabilitation facility services conducted?
  - (c) What were the results?
  - (d) Did the results of this study cause changes in state agency policy, procedures, and/or programs?
  - (e) When is a follow-up study scheduled?
5. What method or procedure does the state unit use to determine that statewide studies contribute to the orderly and effective development of vocational rehabilitation facilities within the state?
  - (a) How does the state unit identify the contributions made by statewide studies to the orderly and effective development of vocational rehabilitation facilities within the state?
  - (b) When was the last study to identify the contributions made by statewide studies to the orderly development and effectiveness of vocational rehabilitation facilities within the state conducted?
  - (c) What were the results?
  - (d) Did the results of this study cause changes in state agency policy, procedures, and/or programs?
  - (e) When is a follow-up study scheduled?

### **Annual Evaluation of Program Effectiveness<sup>8</sup>**

The state unit should conduct an evaluation of the effectiveness of the state's vocational rehabilitation program in achieving service goals and priorities, as established in the State Plan. This evaluation should measure the adequacy of the unit performance in providing vocational rehabilitation services, especially

to those individuals with the most severe handicaps, and should be conducted according to the general standards for evaluation developed by the secretary. Issues to be addressed are

1. What method or procedure does the state unit use to evaluate the effectiveness of the state vocational rehabilitation program in achieving service goals and priorities?
  - (a) How does the state unit evaluate the effectiveness of the state vocational rehabilitation program?
  - (b) When was the last study to evaluate the effectiveness of the state vocational rehabilitation program conducted?
  - (c) What were the results?
  - (d) Did the results of these studies cause changes in state agency policy, procedures, and/or programs?
  - (e) When is a follow-up study scheduled?
2. What method or procedure does the state unit use to measure the adequacy of state unit performance in providing vocational rehabilitation services, especially to those individuals with the most severe handicaps?
  - (a) How does the state unit measure the adequacy of state unit performance in providing vocational rehabilitation services to individuals, especially to those individuals with the most severe handicaps?
  - (b) When was the last study to measure the adequacy of state unit performance in providing vocational rehabilitation services to these individuals conducted?
  - (c) What were the results?
  - (d) Did the results of these studies cause changes in state agency policy, procedures, and/or programs?
  - (e) When is a follow-up study scheduled?

#### **Changes in Policy Resulting from Statewide Studies and Annual Program Evaluation<sup>9</sup>**

Findings derived from the annual evaluations should be reflected in the State Plan, in its amendments, and in development of plans and policies for the

provision of vocational rehabilitation services, either directly by the state unit or within rehabilitation facilities. Issues include

1. What method or procedure does the state unit use to assure the results of statewide studies and annual program evaluations are used to review, change, and/or develop policies for the provision of vocational rehabilitation services directly by the state unit or within rehabilitation facilities?
2. What method or procedure does the state unit use to assure that the results of statewide studies and annual program evaluations are used to estimate the number of handicapped individuals who will be served with funds provided under the Act?

### **State Plan for Rehabilitation Facilities<sup>10</sup>**

The designated state unit should maintain a state rehabilitation facilities inventory that includes those rehabilitation facility services available within the state and a description of the utilization patterns of the facilities and their utilization potential. The inventory should also include (a) a description of need for new, expanded, or otherwise modified rehabilitation facilities or rehabilitation facility services and (b) a prioritized list of facility projects necessary to achieve short-range state unit goals. Issues are

1. Does the state unit maintain a State Rehabilitation Facilities Plan?
2. Does the state rehabilitation facilities plan include an inventory of rehabilitation facility services available within the state and a description of the utilization patterns of the facilities and their utilization potential?
3. Does the state inventory of rehabilitation facility services include a determination of need for new, expanded, or otherwise modified rehabilitation facilities or rehabilitation facility services?
4. Does the state inventory of rehabilitation facilities include a list of facility projects necessary to achieve the agencies short-range goals?

### **Order of Selection for Services<sup>11</sup>**

#### **Outcomes and Service Goals<sup>12</sup>**

If under an order of selection, the state unit should include a statement of (a) the general outcome and service goals to be achieved for handicapped individuals in each priority category within the order of selection in effect in the state and (b) the time within which these goals may be achieved.

These goals should include the objectives, established by the state unit,

which are consistent with those set by the Secretary in instructions concerning the State Plan. These objectives should be (a) measurable, and (b) ones which the state unit intends to achieve during a specified period of time. The issues are

1. What method or procedure does the state unit, under an order of selection, use to establish goals to be achieved for handicapped individuals in each priority category within the order of selection?
2. What is the time frame within which these goals may be achieved?

#### **Methods to Expand and Improve Services to Individuals with the Most Severe Handicaps<sup>13</sup>**

The State Plan should include a description of the methods used to expand and improve vocational rehabilitation services to the most severely handicapped, including a description of the methods to be used to utilize rehabilitation facilities. The issue is

1. What method or procedure does the state unit use to evaluate, expand, and improve vocational rehabilitation services to the most severely handicapped, including methods for utilizing rehabilitation facilities?

#### **Processing Referrals and Applications<sup>14</sup>**

The designated state unit should establish and maintain written standards and procedures on how to assure expeditious and equitable handling of referrals and applications for vocational rehabilitation services. The issues are

1. What method or procedure does the state unit use to establish standards and monitor the expeditious and equitable handling of referrals and applications for vocational rehabilitation services?
  - (a) How were the standards established?
  - (b) When were they established?
  - (c) How are they maintained and changed?
  - (d) How is the use of these standards monitored?

## **State Plan Supplement for Providing Supported Employment Services Title VI, Part C**

### **Statewide Assessment of Supported Employment Services Needs<sup>16</sup>**

The State Plan should include a description of the results of the statewide needs assessment (required under Section 101 (a) (5) (A)) of individuals with severe handicaps to identify the need for supported employment services and the state's response to the assessment. This assessment should indicate the coordination and use of information provided by state special education agencies required by Section 618 (b) (3) of the Education of the Handicapped Act and address the following issue:

1. What is the method or procedure used to determine the need for supported employment services in the state?

### **Description of the Quality, Scope, and Extent of Supported Employment Services<sup>16</sup>**

The State Plan should include a description of the quality, scope, and extent of supported employment services to be provided to individuals with severe handicaps under Title VI, Part C and specify the state unit's goals and plans for the program. The issues are

1. What is the method or procedure used to conduct a statewide assessment of the need for supported employment services?
2. What is the method or procedure used to develop goals and plans for the Supported Employment Program?

### **State Plan for Independent Living Services**

#### **Staffing<sup>17</sup>**

The State Plan should assure that the staff of the designated state unit includes specialist personnel skilled in the coordination and provision of independent living services and similar services to handicapped individuals. The State Plan should also assure that necessary arrangements will be made to ensure the availability of (a) persons able to communicate with severely handicapped individuals who rely on special modes of communication or nonverbal communication devices and (b) personnel able to communicate in the native language of severely handicapped individuals with limited English speaking ability from ethnic groups that represent substantial segments of the population of the community in which the independent living services are being provided.

The issues include

1. What method or procedure does the state unit use to determine the need for independent living rehabilitation services coordinators?
2. What method or procedure does the state unit use to determine the need for persons able to communicate with severely handicapped individuals who rely on special modes of communication (or who have limited English speaking ability)?
3. What is the scheduled time for reassessment?

### **Staff Development<sup>18</sup>**

The state unit should provide for a program of staff development for all classes of positions in providing independent living services within the designated unit. The staff development program must emphasize improving the skills of staff directly responsible for the provision of independent living services. The issues are

1. What method or procedure does the state unit use to determine the training needs of staff involved in providing independent living services?
2. What is the system used to evaluate the effectiveness of staff development activities?
3. How are needs assessment data used to identify new and or different staff development training needs?

### **Establishment and Construction of Rehabilitation Facilities<sup>19</sup>**

The designated state unit should provide for the establishment and construction of rehabilitation facilities. The primary purpose of the establishment and construction of a rehabilitation facility is to ensure the availability of a facility with the capacity to provide independent living rehabilitation services to severely handicapped individuals. The issues are

1. What method or procedure does the state unit use to determine the need to establish and or construct rehabilitation facilities for providing independent living services?
2. Does the state unit have an inventory of rehabilitation facility services need?
3. Does the state unit have a state facilities plan for independent living services?

**Priority for State Unit Clients<sup>20</sup>**

When a program of independent living rehabilitation services is conducted by a local public agency or private nonprofit organization, supported in part under 365.12 (e), the program should be designed primarily to serve those severely handicapped individuals who have been determined by the state unit to be eligible for independent living rehabilitation services under the State Plan. Issues include

1. What method or procedure does the state unit use to assure that needs of vocational rehabilitation eligible clients, who may be referred for independent living services, are met?
2. How is this information used to determine the need to develop independent living rehabilitation services and/or programs?

**State Unit Studies and Evaluation****Scope of Studies<sup>21</sup>**

The state unit should conduct studies of independent living rehabilitation services needs of severely handicapped individuals within the state. These studies should include comparative studies of the different methods for providing these services, such as regional and community centers, centers for independent living, halfway houses, and patient release programs. The State Plan should also assure that the state unit conducts studies to determine effective alternatives to institutionalization. Any studies carried out under the plan should fully utilize findings from relevant studies which have been conducted in the past. The issues to be addressed include

1. What method or procedure does the state unit use to determine the need for independent living services and or programs?
2. What method or procedure does the state unit use to compare different methods for providing independent living services?

**Evaluation<sup>22</sup>**

The state unit should conduct evaluations of the effectiveness of the state's Independent Living Program in meeting the service needs of severely handicapped individuals in the state. These evaluations should measure adequacy of the state's performance in providing independent living services to severely handicapped individuals in the light of program and financial resources in the state. The issue is

What method or procedure does the state unit use to evaluate the

effectiveness of the state's Independent Living Program?

### Use of Findings<sup>23</sup>

Findings from the state unit studies and evaluations should be utilized in planning for and improving future independent living services. The issue is

1. What method or procedure does the state unit use to assure that the findings from state unit studies are used to review, plan, change, and/or develop state unit policy and programs related to independent living services?

### Order of Selection of Services<sup>24</sup>

If the designated state unit cannot furnish independent living rehabilitation services to all severely handicapped individuals who apply and have been determined eligible for independent living rehabilitation services, then an order of selection should be implemented and should be in force in accordance with 34 CFR 365.34. The issues include

1. What method or procedure does the state unit, under an order of selection, use to establish general outcome and service goals to be accomplished for handicapped individuals in each of the independent living categories within an order of selection?
2. What is the time within which these goals may be achieved?

### Provision of Technical Assistance in Poverty Areas<sup>25</sup>

The state unit should undertake special efforts to provide technical assistance to public and other nonprofit agencies and organizations located in areas of urban or rural poverty which are interested in developing capability for providing independent living services. The issues include

1. What method or procedure does the state unit use to determine the need for technical assistance in poverty areas?

### Citation Notes

<sup>1</sup> Section 4.2 Staffing. Sec. 101 (a) (2) (A) (iii), Sec. 101 (a) (7), 34 CFR 361.14.

<sup>2</sup> Section 4.5 Staff Development. Sec. 101 (a) 7, 34 CFR 361.16.

<sup>3</sup> Section 6.2 (d) Utilization of Rehabilitation Facilities. Sec. 101 (a) (12) and (a) (15) 34 CFR 361.22.

- <sup>4</sup> Section 6.2 (e) Services to American Indians Who are Handicapped. Sec. 101 (a) (20), 34 CFR 361.38.
- <sup>5</sup> Section 6.2 (f) Construction of Rehabilitation Facilities. Secs. 7 (1), (10) & (13), 101 (a) (17), Secs. 103 (b) (2) and 34 CFR 361.1(c), 361.21, 361.52, and EDGAR 76.600.
- <sup>6</sup> Section 6.2 (g) Establishment of Rehabilitation Facilities. Secs. 7 (4), 7 (10), 7 (13) and 103 (b) (2), and 34 CFR 361.1 (c) 34 CFR 361.21, 34 CFR 361.51, and EDGAR 76.600.
- <sup>7</sup> Section 8.1 Continuing Statewide Studies and Program Evaluation. Secs. 101 (a) (5) (15) and (19), and 34 CFR 361.2 (b) (1) (ii), and 34 CFR 361.17 (b). 8.1 (a) Statewide Studies.
- <sup>8</sup> Section 8.1 (b) Annual Evaluation of Program Effectiveness. 34 CFR 361.17 (c), EDGAR Secs. 76.101 (e) (4).
- <sup>9</sup> Section 8.1 (c) Changes in Policy Resulting from Statewide Studies and Annual Program Evaluation. 34 CFR 361.17 (c).
- <sup>10</sup> Section 8.2 State Plan for Rehabilitation Facilities. Sec. 101 (a) (15), 34 CFR 361.21.
- <sup>11</sup> Section 8.3 Order of Selection for Services. Secs. 7 (11), 7 (15), 101 (a) (5) (A), 101(a) (13) (B), and 34 CFR 361.36, 361.2 (b) (iv) and (v).
- <sup>12</sup> Section 8.3 (b) Outcomes and Service Goals.
- <sup>13</sup> Section 8.4 Methods to Expand and Improve Services to Individuals with the Most Severe Handicaps. Secs. 101 (a) (5), (10) and (15), 34 CFR 361.2 (b) (2) (iii) and 361.17 (b) (2).
- <sup>14</sup> Section 8.5 Processing Referrals and Applications. Sec. 101 (a) (6) and 34 CFR 361.30.
- <sup>15</sup> Section 1.3 Statewide Assessment of Supported Employment Services Needs. Sec. 634 (b) (2) (A) and 34 CFR 363.11 (b).
- <sup>16</sup> Section 1.7 Description of the Quality Scope and Extent of Supported Employment Services. Sec. 634 (b) (2) (B) and 34 CFR 363.11 (c).
- <sup>17</sup> Section 4.2 Staffing. Sec. 705 (a) (9) and 34 CFR 365.6 (a) and (b).
- <sup>18</sup> Section 4.3 Staff Development. Sec. 705 (a) (9) and 34 CFR 356.7.

<sup>19</sup> Section 6.2 (a) Establishment and Construction of Rehabilitation Facilities. Sec. 702 (b), 34 CFR 365.41, 34 CFR 365.51 and 34 CFR 361.52.

<sup>20</sup> Section 6.2 (e) (5) Priority for State Unit Clients. Sec. 705 (a) (10) and 34 CFR 365.12 (e).

<sup>21</sup> Section 8.1 State Unit Studies and Evaluation. Sec. 705 (a) (2), 34 CFR 365.8 (a), (b) and (c). 8.1 Scope of Studies.

<sup>22</sup> Section 8.1 (b) Evaluation.

<sup>23</sup> Section 8.1 (c) Use of Findings.

<sup>24</sup> 8.2 Order of Selection of Services. Sec. 702 (a), Sec. 702 (a) (2) and (9) and 34 CFR 365.34.

<sup>25</sup> Section 9.6 Provision of Technical Assistance in Poverty Areas. Sec. 705 (a) (7) and 34 CFR 365.10.

4.1

# *Chapter 4*

## **Assessing Needs of Individuals With Severe Disabilities**

### **Background and Discussion**

There are two major influences that have promoted the development of needs assessment for persons with severe disabilities: Consumerism and changes in federal law. During recent years consumer groups have been advocating for a voice in what services they receive and how they are provided those services. As a result, vocational rehabilitation agencies have been required to open up their planning processes to identify needs and provide services to individuals with more severe disabilities. Federal law and the regulations adopted on May 12, 1988, require state agencies to continually assess the vocational and related needs of their consumer populations and use that information to modify or develop services to meet appropriate needs.

Federal regulations (the amended Rehabilitation Act of 1973) require state agencies on a continuous basis to conduct statewide studies of the needs of individuals with handicaps within the state, including (a) a comprehensive, statewide assessment of the rehabilitation needs of individuals with severe handicaps residing within the state, (b) an assessment of the need for supported employment services throughout the state, (c) an assessment of the capacity and condition of rehabilitation facilities to provide needed services throughout the state, (d) an assessment of the state's needs for rehabilitation facilities and the methods by which these needs may be most effectively met, and (e) an assessment of the relative needs for vocational rehabilitation services of different significant segments of the population of handicapped individuals.

### **Some General Consideration in Designing Needs Assessments**

Providing the tools for conducting rehabilitation needs assessment by the state agency is the focus of Volume II. As readers go about considering the need for and designing these special studies, their selection of design and tools should proceed only after they have carefully considered the following: (a) requirements and meaning of the legislative mandates for services at both the state and federal levels; (b) definition of the target population or program; (c) examination of the vocational rehabilitation program structure in relation to the total state service delivery system; (d) past management decisions for resource allocations relevant to program delivery; (e) availability and quality of current information on needs; and (f) the agency's purpose, intended utilization, and resources for conducting a needs assessment effort.

Some of the kinds of considerations that are more fully discussed in the next several chapters can be abstracted here. The following are general

considerations that should be made when planning needs assessment studies of various segments of the population of persons with severe disabilities:

1. The needs of many of the targeted groups can be studied using a general needs assessment approach if appropriate sampling considerations (e.g., stratified, oversampling), instrument variations (e.g., alternate formats, response modes), and alternate data collection techniques (e.g., allowing use of both consumer and consumer representatives) are included in the design. This is desirable since quite often there is a program need to evaluate common, unique, and/or relative levels of need among different groups.
2. A single methodology will not work in all cases, however. Assessments of needs based on self-reports, for example, may have limited validity because personal responses may be restricted by culture and specific impacts of disability. A series of studies or variety of approaches may have to be used to accurately understand needs of certain cultural populations (e.g., using tribal leaders to solicit needs) and disability populations (e.g., validating responses through family members).
3. Methodologies must include provisions to assure that the samples are representative of the targeted population and any subgroup to which results are to be reported. A study which adheres to a random sampling approach may only generate a few responses from a specific minority or underrepresented population. Oversampling of specific groups of people or in a geographic sector may be required in order to include enough persons with the identified disability or cultural background to allow the agency to reliably identify needs.
4. Language barriers (due to communication skill limitations or to cultural differences) must be anticipated and addressed in the methodology. This will likely require preparation of multiple formats for collecting data (e.g., in expanded type, in audio form, in alternate language formats, administration by a minority person).
5. Problems typical of those encountered in gathering data and determining the rehabilitation needs of individuals identified in the legislation for needs assessment include the following:
  - a. Individuals may be clustered in specific locations or may be very widely dispersed across the state.
  - b. Individuals may have special communication problems that either limit their ability to indicate specific need or require very specific data collection efforts.
  - c. Individuals in the target groups may be unaware of their needs,

unable to articulate their needs, or unable to relate their needs to what rehabilitation may be able to provide.

- d. Individuals in the targeted groups are likely to be members of more than one targeted segment, and this must be considered both in sampling and in analyzing results for program planning.
- 6. If such decisions as "order of selection" and priority setting for developing service programs are to be made, greater resources (fiscal and technical) are needed to insure that such decisions are based on the most accurate objective information available on needs of different segments of the potential client population.

### **Special Considerations in Assessing the Needs of Persons with Severe Disabilities**

There are problems in obtaining valid information on the vocational needs of persons having certain severe disabling conditions due to the specific limitations resulting from the disability. All procedures discussed in this manual, including surveys of the general population, should attend to these issues in order to circumvent those limitations. Failure to do so will likely invalidate the needs data otherwise carefully collected. The procedures used in the needs assessment must be sensitive and adjust for the difficulties that persons with physical and cognitive disabilities have in responding to interviews and surveys. These procedures must also attend to the simple humane and ethical considerations for the feelings and privacy rights of the people we involve and intend to serve as a result of the research.

- 1. Any interview or survey must be introduced in a way that motivates potential respondents to respond. In order to do this, the interviewer, survey staff, or introductory materials should clearly and simply inform the respondents of the purpose of the survey, how their participation might help them, how data from it will be used to improve services, and why it is worth their time to participate.
- 2. All instruments should be free of jargon or terms that are not understood and meaningful to the population being asked to participate.
- 3. The language of all instruments should be evaluated and set to the lowest grade level possible while still getting across the intended message. There are several "fog indexes" available that can be used for this purpose, including some inexpensive ones for personal computers.
- 4. All needs assessment instruments should be available and administered in the respondent's native language (including sign language).

5. Needs assessment instruments must be free of cultural biases and stereotypes.
6. Appropriate demographic information needed to identify cultural characteristics as well as disability characteristics should be gathered if the data are to be used to estimate the specific needs for these subpopulations.
7. Some persons with severe physical disabilities have a difficult time in carrying out tasks that most people take for granted such as opening envelopes, handling paper, writing, and mailing responses. Because they do, if responding to the survey does not fit into their established routines for handling correspondence, they may be inclined to ignore the request (e.g., such as when they have arranged for assistance in taking care of mail handling chores). It may be advantageous to send surveys out near the end of the month when people are likely to be paying bills and dealing with other correspondence.
8. Individuals with physical disabilities also have difficulty manipulating light-weight paper. It is also important that the survey itself be designed for easy handling such as using three-fold light cardboard sealed with tape or stickers rather than staples. The instruments should also be easily resealable.
9. Individuals with developmental disabilities (e.g., mental retardation) usually have a significant impairment in their ability to read and/or to understand written correspondence. Use of written surveys will be ineffective in identifying their needs. Several alternatives to sending written surveys to this population that can be used (although each has its own set of limitations) are face-to-face personal interviews, telephone interviews, and use of focus groups to identify and discuss needs.
10. When conducting interviews, the type of interview used is dependent on the purpose for which the interviews are held.
11. Personal interviews and focus group sessions are useful when the purpose is to obtain information on the needs of a particular grouping of individuals or on a particular topic such as work conditions, housing arrangements, social interests or activities, or common medical needs.
12. Telephone interviewing is an alternative method for conducting general surveys such as prevalence studies. It has the advantage over written surveys in that the surveyor is able to clarify questions and relate to respondents in warmer and more personal ways, which should be reflected in higher return rates for acceptable surveys.

### **Important Sources of Information on Needs of Persons with Severe Disabilities**

This following are typical information sources that a state might use to gather relevant background information about need. Many of the sources identified may be valuable as sources of "knowledge about needs." Others will be valuable because of the reports and studies they have conducted. The list is not exhaustive but rather is representative of the many sources available to obtain information on specific aspects of the needs of persons with disabilities. Some of these sources may also include agencies with staff who could be queried from a professional or key informant perspective on client needs.

#### **General Sources of Information**

**Service Providers.** Many of these service providers will have significant and relevant knowledge about disabilities, needs, and programs:

Vocational rehabilitation counselors, counselors with specialized caseloads, facility specialists, and other rehabilitation professionals.

Rehabilitation facilities and their state and national associations (e.g., Goodwill Industries, National Industries for Severely Handicapped, National Association of Rehabilitation Facilities, Jewish Vocational Services).

Rehabilitation agencies and field offices, including those in one's own state, in neighboring states, and those in one's own state that are not approved for services under authority of agencies coordinating the 110 program.

Extended employment programs (e.g., supported employment programs).

State and local special education programs.

Human service and welfare programs at county and state levels.

Outpatient and acute care hospitals and clinics.

Mental health hospitals and clinics.

Long-term and intermediate care institutions.

Private service providers (e.g., drug treatment centers) and nursing home staff.

**Public and Private Agencies.** Many studies are periodically conducted by various local, state, or regional agencies to identify needs, programs, and population characteristics; these studies and/or agencies include the following:

State data systems will often contain significant information on the people living in the state. While set up for other purposes, they will sometimes contain data of use in planning the assessment. When available, they are most often maintained by departments of health, labor, commerce, welfare, tourism, or education.

Federal and state studies conducted with rehabilitation and special education funding (e.g., by RSA Regional Offices).

Studies conducted on behalf of regional training and demonstration grants sponsored by the U.S. Departments of Education, Health, Mental Health, Developmental Disabilities, Labor, Housing, Transportation.

State and private universities receiving grants and contracts for developing rehabilitation and special education training, for providing inservice education, and for conducting research and development projects on youth, vocational and medical studies of disabilities, rehabilitation facilities, and special education.

State, county, and local agencies, including welfare agencies, developmental disabilities boards and councils, mental health boards, transportation authorities, and housing authorities.

Telephone companies and providers of adaptive technology for home and work use.

Foundations and advocacy associations conducting and sponsoring research and development of services and devices for youth and adults with disabilities.

### **Federal Rehabilitation and Related Agencies**

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave. SW, Washington, DC 20202-2572; (202) 732-1192.

Rehabilitation Services Administration (RSA); Office of Special Education and Rehabilitation Services, U.S. Department of Education,

Switzer Building, 330 C Street SW; Washington, DC 20202; (202) 732-1282.

**Regional Offices, Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitation Services, U.S. Department of Education.** A listing of the 10 offices is contained in Appendix J.

**Administration on Developmental Disabilities (ADD), Office of Human Development Services, U.S. Department of Health and Human Services, Room 348F, HHH Building, 200 Independence Ave. SW, Washington, DC 20201; (202) 245-2890.**

### **Federally Funded Centers**

**Rehabilitation Research and Training Centers.** There are 40 Centers funded by the National Institute of Disability and Rehabilitation Research established to conduct programmatic research on vocational, medical, social, disability, and ethnicity-related problems and issues. Many of these Centers focus on priorities parallel to those identified in the Rehabilitation Act. Their research, bibliography, and progress reports are significant resources on needs data. A list of Centers and their mission areas is contained in Appendix E. An updated list can be obtained from NIDRR (listed above).

**Rehabilitation Engineering Centers.** There are 15 Centers funded by the National Institute of Disability and Rehabilitation Research established to develop, test, adapt, or evaluate commercial and noncommercial devices for persons with a wide range of physical, cognitive, and developmental disabilities. Many of these Centers focus on priorities parallel to those identified in the Rehabilitation Act. Their publications and progress reports are significant resources on needs data. A complete list of Centers and their mission areas is contained in Appendix H. An updated list can be obtained from NIDRR.

**University Affiliated Programs.** These are programs funded by the Administration for Developmental Disabilities at universities throughout the United States. Many of these programs work quite effectively with state developmental disabilities councils to study problems and needs of persons with disabilities that are classified as developmental, rather than acquired, though the difference is not always clear (e.g., some states include traumatic brain injury as developmental). The programs in a given state can be reached by contacting either the Administration for Developmental Disabilities (listed above) or the American Association of University Affiliated Programs for Persons With Developmental Disabilities (AAUAP), 8605 Cameron St., Suite 406, Silver Spring,

MD 20910, (301) 588-8252.

### **Public and Private Universities and Colleges.**

Institutions of higher education often have rehabilitation, special education, psychology, and educational psychology programs with staff and expertise on assessment and disability specific issues. These institutions will also often have sociology programs and Native American studies, ethnic studies programs, women's studies programs, and other culture-specific programs. Staff in these programs can be a valuable resource for developing sensitivity to the cultural mores and for acquiring knowledge of appropriate ways to elicit needs data. They may also be of help in interpreting the meaning of those needs assessment data once obtained.

### **Resource Directories and Clearing houses.**

These directories, national clearing houses, and information centers maintain current and historic information and collections of data on disabilities and program needs.

National Institute of Handicapped Research, Office of Special Education and Rehabilitation Services, U.S. Department of Education. (1986). *Directory of National Information Sources on Handicapping Conditions and Related Services*. Washington, DC: U.S. Government Printing Office, Washington, DC, 20402.

ABLEDATA, Adaptive Equipment Center, Newington Children's Hospital, 181 East Cedar Street, Newington, CT 06111, (800) 344-5405.

Materials Development Center, University of Wisconsin-Stout, Menomonie, WI 54751, (715) 232-2419.

National Clearing House of Rehabilitation Training Materials (NCHRTM), Oklahoma State University, 115 Old USDA Bldg., Stillwater, OK 74078, (405) 875-7650.

National Rehabilitation Information Center, 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

U.S. Census annual studies of population changes. These studies and data are compiled into a variety of resource documents available through the U.S. Department of Labor. The data are also prepared and marketed by several private firms for specific marketing purposes.

National Health Surveys conducted by the U.S. Health Service and the Center for Disease Control.

**Disability Registries.** Registries for certain disabilities and groups are established and maintained at both national and state levels and, occasionally, in large urban areas as well. Some groups for whom registries are often found established are spinal cord, head injury, blindness, and aging.

**President's Committee.** The President's Committee on Employment of the Persons with Disabilities; Vanguard Building, Suite 636; 1111 20th St. N.W., Washington, DC 20036; (202) 653-5080.

**Client Advocacy Organizations.** A list of some of these organizations is included in Appendix K. A sampling of such organizations include United Cerebral Palsy, National Association for the Deaf, Alliance for the Mentally Ill, National Association for Retarded Citizens, Epilepsy Foundation, The Association for the Severely Handicapped, National Association for the Blind or American Federation for the Blind, and Association for Retired Persons.

### **Selected Bibliography**

Association journals and the bibliographies prepared by research centers and projects are vital sources of information on needs and methods for assessing needs.

American Psychological Association. (1973). Ethical principles in the conduct of research with human participants. Washington, DC: Author.

Auvenshine, C. D., & Mason, E. J. (1982). Needs assessment in planning rehabilitation services. Journal of Rehabilitation Administration, 6(2), 56-62.

Babbie, E. R. (1973). Survey research methods. Belmont, CA: Wadsworth Publishing Co.

Bennett, E. C. (1975). Estimating need and demand for vocational rehabilitation services. In I. P. Robinault (Ed.), Program planning and evaluation, selected topics for vocational rehabilitation (pp. 7-17). New York: ICD Rehabilitation and Research Center, Research Utilization Laboratory.

Berdie, D. R., Anderson, J. F., & Niebuhr, M. A. (1986). Questionnaires: Design and use. New York: The Scarecrow Press.

Berkowitz, E. D. (1987). Disabled policy: America's programs for the

handicapped. New York: Cambridge University Press.

Bowe, F. (1985). Disabled adults in America: A statistical report drawn from Census Bureau data. Washington, DC: President's Committee on Employment of the Handicapped.

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Chilman, C. S., Nunnally, E. W., & Cox, F. M. (Eds.) (1988). Chronic illness and disability. Beverly Hills, CA: Sage Publications.

Collington, F. (1984). Estimating need for rehabilitation services for use in program resource allocation in the state of Maryland, VR Techs Monograph Series. Berkeley, CA: 22 p.

Ellis, D. (Ed.) (1986). Sensory impairments in mentally handicapped people. San Diego, CA: College-Hall Press.

Fawcett, S. B., Cyzewski, M. J., & Lechner, M. (1986). A grassroots approach to policymaking for persons with physical disabilities. Journal of Rehabilitation, 52(1), pp. 59-63.

Goldman, C. (1987). Disability rights guide: Practical solutions to problems affecting people with disabilities. Lincoln, NE: Media Pub.

Hutchinson, I. (1978). User's Guide To Needs Assessment Technologies. Tallahassee, FL: Department of Health and Rehabilitative Services.

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National Easter Seal Society. (1984). Conducting Needs Assessment: A Program Portfolio Resource Manual. Washington, DC: Author.

Neuber, K. A. (1980). Needs assessment: A model for community planning, Sage Human Services Guides, Vol. 14. Newbury Park, CA: Sage Publications.

Ohio Department of Mental Health. (1983). The mental health needs assessment puzzle: Guide to a planful approach. Columbus, OH: Author.

Struthers, R. D. (1986). Methods to obtain and use information about the number of people needing rehabilitation services and the services needed. Lansing, MI: Michigan Rehabilitation Services Division.

Witkin, B. R. (1984). Assessing Needs in Educational and Social Programs. San Francisco, CA: Jossey-Bass Publishers.

Wood, P. H., & Badley, E. M. (1981). People With Disabilities -- Toward Acquiring Information Which Reflects More Sensitive Their Problems and Needs, World Rehabilitation Fund, International Exchange of Information in Rehabilitation Monograph #12.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

### **Resources for Assistance**

This section consists of public or private survey research organizations that could either conduct or assist your agency in designing and or conducting prevalence of disability studies.

**Client Advocacy and Professional Organizations.** These organizations are not only useful for information on population and professional need but they may also be willing to participate in planning and utilization of needs assessments. Some organizations have very active state and local affiliates that may also be helpful in finding persons with disabilities and in conducting various parts of the assessment.

**Rehabilitation Research and Training Centers.** Not all these Centers have the resources to carry out a needs assessment effort for a state, but their staff are knowledgeable resources in conceiving and utilizing needs assessments.

**Rehabilitation Engineering Centers.** These Centers are mission based, and while they are not funded to conduct needs assessments, they can be a valuable resource in design and utilization of needs assessment findings.

**Public and Private Universities and Colleges.** Institutions of higher education often have rehabilitation, rehabilitation administration, special education, psychology, and educational psychology programs with staff and expertise on assessment and disability specific issues. Staff in these programs can be a valuable resource for developing, conducting, and in interpreting the meaning of those needs data once obtained.

**Research Institutes and Firms.** Institutes are often located on major university campuses, but they may also be private, non-profit or for-profit enterprises. Some will have funding that enables them to provide some services with minimal or no cost; others must recover full costs for their services. From these organizations an agency can purchase services for virtually any stage of

the assessment activity, ranging from designing a sample, to collecting data, to preparing reports from those data, to conducting public hearings.

**University Affiliated Programs.** The programs are funded by the Administration for Developmental Disabilities at universities throughout the United States and work with state developmental disabilities councils. They will frequently be interested in assisting on studies of the needs of persons with developmental disabilities.

## *Chapter 5*

### **Chronic Mental Illness**

#### **Background and Discussion**

Vocational rehabilitation services provided to chronically mentally ill clients typically have been less effective than those provided to other groups in recent years. As a result, initiatives have been undertaken at the federal and state levels to improve services. Mental health and rehabilitation professionals have been encouraged to collaboratively improve services to those with chronic mental illness through a variety of mechanisms including facility grants. Job coaching, crisis intervention, and post-employment follow-along services usually have been emphasized in transitional employment (Perlman, 1980; Hansen & Perlman, 1988).

Section 34 CFR 361.17(b)(1) of the regulations for the 1973 Rehabilitation Act, as amended in 1986, requires state agencies to "Determine the relative need for Vocational Rehabilitation services of different segments of the population of individuals with handicaps." The chronically mentally ill comprise a significant portion of this population. According to analyses of census data reported by Frank Bowe (1987, p. 20), there are about one million non-institutionalized Americans age 16 years or older with severe mental illness. While the definition of chronic mental illness Bowe used in his analyses may not coincide with the one applied by vocational rehabilitation professionals, the size and unique needs of this group make it impossible to ignore.

In addition, Section 34 CFR 361.1(c)(2) Supported Employment(B)(ii) states:

Transitional employment for individuals with chronic mental illness as used in the definition of Supported Employment means competitive work in an integrated work setting for individuals with chronic mental illness who may need support services but not necessarily job skills training services provided either at the work site or away from the work site to perform the work. The job placement may not necessarily be a permanent employment outcome for the individual.

Therefore, the chronically mentally ill, while not yet formally defined, comprise a key target group for supported employment services. As a result, a needs assessment for supported employment services, as required by Section 34 CFR 363.11, should consider the needs of persons with chronic mental illness in their statewide assessments.

Estimates of the size, location, and service needs of the chronically mentally ill population can help determine if this group is being underserved or overserved in relation to other groups. In addition, to parity with respect to program coverage and representation issues, the recidivism rate for the

chronically mentally ill could be compared to the rates for other disability groups. Compared to other disability groups, the chronically mentally ill may be more likely candidates for supported employment services. The number and location of the chronically mentally ill who need this type of service should be part of the basis for an operational supported employment plan. Their needs also can have implications for the types, quantity, and location of planned facility services, the rehabilitation facility plan inventory, and in-service training for state agency and facility staff. Availability of public and private transportation and residential services are likely to be of prime importance to this group. Their needs should also impact on operational plans for other vocational rehabilitation and independent living services.

### Definition

Despite public and legislative efforts, no federal definition of chronic mental disability has emerged. In the interim, Matrix Research Institute (1988) suggested the following definition of long-term mental illness used in a recent service provider survey: Chronic mental illness is "...a condition of impaired mental health, of long term prognosis, with possible remissions and uncertain outcome that may disable the affected individual for extended periods of time." In contrast, some states define chronic mental illness, for the purpose of rehabilitation facility grants, as a psychiatric impairment of long-term duration having required at least two hospitalizations.

The lack of agreement on what constitutes chronic mental illness is the greatest single impediment to building a comprehensive picture of the rehabilitation service needs for this group. It is difficult to relate or compare the results of different studies based on varying definitions of chronic mental illness. Without use of a common definition, each successive study in essence must start over at square one and stand alone.

### Disability Related Characteristics Affecting Assessment

Certain problems that arise from this disability can affect an individual's ability to fully represent their needs. Some of these arise from the impact of the disability on the individual themselves, while others result from society's reactions to mental illness.

**Perception.** Persons with mental illness are often not aware of their own illness and symptoms. They may also not be aware of their diagnosis, medications, treatment, names and types of rehabilitation services they are receiving, and the names of agencies and professionals from whom they are currently receiving services.

**Comprehension.** Due to symptoms of mental illness and cognitive

deficits, some persons with mental illness may have difficulty following and understanding complex directions. They may misunderstand the purpose or intended use of the information.

**Thought Patterns.** Dysfunctional thought patterns and problems or ideas of reference and anxiety may interfere with an individual's ability to respond accurately when reporting his/her needs (e.g., on a survey).

**Medication Side Effects.** Psychotropic medications used to treat symptoms of mental illness may cause blurred vision, poor finger dexterity, and tremors in hands, which may lead to difficulty in completing written surveys or writing in small spaces.

**Lack of Initiative.** Persons with mental illness may have difficulty initiating and completing tasks due to cognitive difficulties or as a result of psychotropic medications. Length of the interview or questioning and how to elicit needs may require special skills and consideration in designing interviews and instruments.

**Loss of Identity and Self-Esteem.** Persons with long-term unemployment due to mental illness may view themselves as incompetent and unable to work. Their responses to surveys may reflect this hopelessness and apathy, rather than needs.

**Poor Interpersonal Skills.** A common problem associated with mental illness is a difficulty in forming and maintaining relationships. Persons with mental illness may be suspicious of anyone inquiring about their lives (either in writing or in person).

**Stigma.** Mental illness is a very stigmatizing disability and has had very poor public acceptance. Persons with mental illness may be reluctant to acknowledge that they have a history of mental illness and may hide their illness for fear of discrimination.

### **Needs and Difficulties in Serving Persons with Mental Illness**

Chronically mentally ill clients typically have needs that make it difficult to serve them. Among those most frequently cited in the literature are the following:

**Employer Perceptions.** The stigma of mental illness makes it hard to convince some potential employers to hire chronically mentally ill clients.

**Evaluation Tools.** Traditional or standard vocational evaluation tools have low predictability; situational assessments seem to work better with the

chronically mentally ill.

**Apparent Motivation.** Rehabilitation counselors have traditionally had difficulty motivating chronically mentally ill clients.

**Periodic Recurrences.** Periodic emotional crises undermine placements and increase recidivism rates for this group as compared to other disability groups. Rate of recidivism is the percentage of clients who reapply for services within a given time period (e.g., one or two years after job placement).

**Indeterminant Ongoing Needs.** Follow-along services such as those that can be provided through supported employment may have the potential for moderating the effects of emotional crises and, therefore, placements of persons with chronic mental illness.

**Transience.** Many mentally ill individuals attempt to function on the fringes of society. They are often difficult to locate due to frequent moves or lack of any permanent address. America's homeless population may include a sizable portion of chronically mentally ill persons.

**Housing and Transportation Needs.** Housing often is a problem for this group. Many chronically mentally ill individuals need a supportive environment provided by a group home. However, the stigma associated with group homes makes it difficult to provide this type of housing. Transportation also tends to be a problem. Many mentally ill individuals do not have access to private transportation, especially to get to and from work. In areas where public transportation is unavailable, these individuals often find themselves without any transportation at all. Therefore, housing and transportation should be considered in assessing the needs of this group.

**Differences in Agency Philosophies.** Finally, there is a difference in philosophy between mental health departments and vocational rehabilitation agencies. Mental health service providers tend to embrace a long-term maintenance orientation while vocational rehabilitation professionals tend to take a goal-oriented, time limited approach to service delivery. These contrasting perspectives tend to complicate collaborative efforts of vocational rehabilitation and mental health providers, as well as color the input which specific service providers might provide to the needs assessment.

### **Special Considerations in Assessing the Needs of Persons with Chronic Mental Illness**

A variety of approaches may be required to obtain a comprehensive picture of the service needs of the chronically mentally ill. Among those that are available, key informant and service provider surveys are probably the most

productive approaches for several reasons. First, individuals with chronic mental illness who are not connected with the mental health service delivery network tend to be difficult to locate, especially in rural areas. Second, individuals with chronic mental illness do not as a rule represent themselves well in public and especially at public forums. In many cases, their ability to represent themselves may be called into question. Regardless of the approach or approaches taken, needs assessments should be conducted and applied in a manner that enhances consumer involvement. Increased consumerism is perceived by experts as crucial in improving services for the mentally ill.

Several considerations in assessing the needs of this population follow:

1. The stigma associated with chronic mental illness may make it both difficult to locate these populations and, once located, to obtain their participation. State associations and support groups may be sources for identifying particularly articulate individuals.
2. Care will be needed to assure clients that the information will not be used against them. Personal interviews may be a more productive method than either telephone interviews or mail surveys. Tape recordings of interviews may not be advisable. Special precautions may even require reviewing their responses with them, using "blinds" and safe postal boxes.
3. Special care will be required to obtain information on continuing non-vocational needs for housing and transportation, intermittent support and counseling, and other follow-along services, as well as vocational needs.
4. Dysfunctional thought patterns (resulting from the illness and controlling drugs) will make it difficult for many chronically mentally ill persons to accurately relate their needs. Interviews should be short, open, and direct. It may be appropriate to limit the number of alternatives when multiple choices are provided for selection or ranking. Precautions for validating expressed need should be anticipated in designing and collecting assessment data from individuals.
5. Counselors and advocates may provide some of the more accurate information on basic needs from their reviews of individual case files and from individual histories.
6. Support groups (or case managers if the individual is active with an in-patient or out-patient program or service) may be a source for collecting needs data or setting up group meetings in which needs might be discussed.

### **Suggested Sources of Information on Needs of Persons with Chronic Mental Illness**

#### **Organizations and Associations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of persons with chronic mental illness. They may be of help for identifying service providers and key informants for person with mental illness. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

American Association of Psychiatric Services for Children (AAPSC), 1133 Fifteenth St., NW, Suite 1000, Washington, DC 20005, (202) 429-9713.

International Association of Psychosocial Rehabilitation Services (IAPSRS), P.O. Box 278, McLean, VA 22101, (703) 237-9385.

National Alliance for the Mentally Ill, Fox Den Farm, 2601 Catnip Hill Road, Nicholasville, KY 40356, (606) 887-2851.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Institute on Mental Health, (Alcohol, Drug Abuse, and Mental Health Association, Health and Human Services Dept.), 5600 Fishers Lane, Rockville, MD 20857, (301) 443-3673.

National Mental Health Association, 1021 Prince St., Alexandria, VA 22314-2971, (703) 684-7722.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

State departments of mental health, county mental health departments, local mental health centers, mental health associations, and state chapters of the Alliance for the Mentally Ill often are able to provide some prevalence, incidence, and social indicator data and can also help identify service providers and key informants.

### **Research Centers and Projects**

**Rehabilitation Research and Training Center for Psychiatric Rehabilitation, Center for Psychiatric Rehabilitation, 730 Commonwealth Avenue, Boston, MA 02215. William A. Anthony, Ph.D., Project Director, (617) 353-3549.**

**Rehabilitation Research and Training Center on Children's Mental Health, University of South Florida, Florida Mental Health Institute, 13301 Bruce B Downs Boulevard, Tampa, FL 33612. Robert M. Friedman, Ph.D., Project Director, (813) 974-4500.**

**Rehabilitation Research and Training Center in Child Trauma, Tufts-New England Medical Center, Department of Rehabilitation Medicine, 750 Washington Street, Box 75K/R, Boston, MA 02111. Stephen M. Haley, Ph.D., Project Director, (617) 956-5031.**

**Rehabilitation Research and Training Center on Improving Services for Seriously Emotionally Handicapped Children and Their Families, Portland State University, Regional Research Institute for Human Services, P.O. Box 751, Portland, OR 97207-0751. Barbara Friesen, Ph.D., Project Director, (503) 464-4040.**

**Rehabilitation Research and Training Center on Families and Disability, Beach Center, University of Kansas, Bureau of Child Research, 2045 Haworth Hall, Lawrence, KS 66045. Ann P. Turnbull, Ed.D., Co-Project Director; H. Rutherford Turnbull, LLB, LLM, Co-Project Director, (913) 864-4295.**

**Rehabilitation Research and Training Center in Pediatrics, University of Connecticut Health Center, Department of Pediatrics, Division of Child and Family Studies, The Exchange, Suite 164, 170 Farmington Avenue, Farmington, CT 06032. Mary Beth Bruder, Ph.D., Project Director, (203) 674-1485.**

**Rehabilitation Research and Training Center on Mental Health Rehabilitation of Individuals With Deafness, University of California-San Francisco, Center for Deafness, 3333 California Street, Suite 10, San Francisco, CA 94143. Mimi W. P. Lou, Ph.D., Acting Director/Training Director, (415) 476-4980.**

Rehabilitation Research and Training Center on Individuals with Chronic Mental Illness, Boston University, Sargent College of Allied Health Professions, 881 Commonwealth Ave., Boston, MA 02215. William Anthony, Ph.D., Project Director, (617) 353-3549.

Rehabilitation Research and Training Center for Emotionally Disturbed Children, University of South Florida, Florida Mental Health Institute, 33301 North 30th St., Tampa, FL 33612. Robert Friedman, M.D., Project Director, (813) 974-4610.

Rehabilitation Research and Training Center for Psychiatrically Disabled Individuals, Yeshiva University, Albert Einstein College of Medicine, 1300 Morris Park Ave., New York, NY 10461. Seymour Kaplan, M.D., Project Director, (212) 824-6150.

Rehabilitation Research and Training Center for Rehabilitation of Long-Term Mental Illness, Threshold Research Institute, 561 Diversey Parkway, Suite 210A, Chicago, IL 60614. Judith Cook, Ph.D., Project Director, (312) 348-5522.

Matrix Research Institute, Kenilworth # 106, 2979 School House Lane, Philadelphia, PA 10144.

Supported Employment for Chronically Mentally Ill, Boston University, Sargent College of Allied Health Professions, 881 Commonwealth Avenue, Boston, MA 02215. William Anthony, Ph.D., Project Director, (617) 353-3549.

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### Standard Resources for Assistance

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with mental illnesses and support groups.

Psycho-social and vocational rehabilitation centers.

The Research and Training Centers with missions in the areas of inquiry listed above.

Universities and colleges with rehabilitation and psycho-social programs concerned with training and research on the unique differences and disabilities of these populations.

# *Chapter 6*

## **Developmental Disabilities**

### **Background and Discussion**

The Developmental Disabilities Act of 1984 defines a developmental disability as a severe, chronic disability of a person that

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the person attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive expressive language, learning, mobility, self direction, capacity for independent living, and economic self-sufficiency; and
5. Reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned or coordinated.

Section 34 CFR 361.17(b)(1) of the regulations for the Rehabilitation Act of 1973, as amended in 1986, requires state agencies to "Determine the relative need for Vocational Rehabilitation services of the different segments of the population of individuals with handicaps." When the Developmental Disabilities Act of 1984 was enacted, it was estimated that there were more than two million developmentally disabled Americans. However, in ensuing years, as refinements were made in the scope of the federal definition, the size of the target population is now estimated to be around 1.7 million or .8 percent of the total American population (Hagen, 1988, p. 23). This group, nevertheless, constitutes a significant portion of the population of individuals with disabilities who are likely to have life-long vocational and related needs (e.g., housing, transportation).

### **Disability Characteristics and Needs Assessment**

Three of the major disabling conditions most often included in the definition of developmental disabilities are mental retardation, cerebral palsy, and epilepsy. Individuals in each of these groups present special challenges to needs assessment. While traumatic brain injury is included under developmental disabilities in some states, this disability is covered in a separate chapter.

**Mental Retardation.** Individuals having this disability usually have a significant impairment in their ability to read and understand written correspondence, which make written surveys ineffective in identifying their needs. There are several alternatives to sending written surveys to this population that can be used although each of them has its own sets of limitations: Personal interviews, focus groups of disabled persons, and telephone interviews.

The type of interview used is dependent on the purpose for which the interviews are held. Personal interviews and focus group sessions are useful when the purpose is to obtain information on the needs of a particular grouping of individuals or on a particular topic such as work conditions, housing arrangements, social interests/activities, medical needs, etc.

Telephone interviewing is an alternative method for conducting general surveys such as prevalence studies. It has an advantage over written surveys in that the surveyor is able to clarify questions and relate to respondents in warmer and more personal ways, which may reflect on the return rate of acceptable surveys.

**Cerebral Palsy.** Persons with this disability have motor coordination problems that may affect different parts of their body in varying degrees. Some will have great difficulty producing intelligible speech and may depend on computerized speech devices or manually operated communication boards. This impairment, commonly found with severe cerebral palsy, makes telephone interviews a risky and slow procedure. Telephone interviews may be used successfully, but some individuals may need to speak through a family member or other individual skilled in their mode of communication.

An even greater proportion of individuals with cerebral palsy, however, lack the fine motor coordination required for legible writing so that written surveys are difficult and time-consuming for them, and their responses may be difficult to read. Since many persons with cerebral palsy have substantial mobility impairments, public forums or arranged interviews should be held in accessible locations. Personal interviews that allow for a mutual adjustment in communication for both the interviewer and interviewee are the preferred method of sampling the views and needs of this population.

**Epilepsy.** Individuals with a history of seizures may be taking medications that slows down their verbal responses and, in some cases, limit their comprehension of interview or survey questions. Since persons with this disability present such a wide variety of abilities and limitations, it is difficult to generalize about preferred needs assessment techniques. Since epilepsy is a neurological disorder, many of the impairments discussed under learning disabilities and traumatic brain injury apply, but probably at lower rates for this

group than the other groups.

Some of the major issues that persons with epilepsy face is a lack of understanding and fear on the part of others around them and their own fears about having seizures. These concerns may make a person with a seizure history hesitant to respond to surveys. Telephone interviews, if conducted with care and sensitivity, should be more productive than written questionnaires.

### **Use of Needs Assessment Results in the State Plan**

Estimates of the size and rehabilitation service needs of the developmentally disabled population can help determine if this group is being underserved or overserved in relation to other disability groups. Service provider and key informant input can help define service gaps that have implications for operational plans for a variety of programs such as supported employment, independent living, and the regular vocational rehabilitation program. These needs, as well as needs for accessible housing, residential services, and accessible transportation may have impact on the State Plan. As a sizable number of developmentally disabled persons are also severely disabled, most initiatives to fulfill their unmet service needs can be described in the State Plan narrative on methods for improving services to the most severely disabled.

### **Special Considerations in Assessing the Needs of Persons with Developmental Disabilities**

A variety of approaches may be needed to obtain a valid picture of their service needs because some developmentally disabled individuals have communication deficits as well as unique needs. Prevalence and incidence studies may need to be conducted on a face to face basis to assure representative results, which makes this approach relatively expensive. For the same reason, testimony gleaned from developmentally disabled individuals at community forums may not be particularly representative. Therefore, key informant and service provider surveys appear to offer the most cost effective methods for obtaining representative information concerning the rehabilitation service needs of the developmentally disabled.

Special considerations in assessing the needs of this population follow:

1. Each state's developmental disabilities council is required to publish a three year State Plan. Moreover, their Plan must contain the results of an assessment of the service needs of the developmentally disabled residing within the state. These findings usually are derived by applying prevalence rates developed elsewhere to the latest population estimate for the state. Their findings can be an important first step upon which to build further assessments, and collaboration with those councils may be worthwhile.

2. The research on needs of the developmentally disabled suffers from lack of comparability due to the variety of definitions currently in use. Agreement on a single definition of developmental disability used by all programs serving this group in all states is needed in order to obtain comparable findings, particularly where other agencies' resources might be involved.
3. Close coordination between the state developmental disabilities council and advocacy organizations is recommended since much needs assessment information useful to vocational rehabilitation already may have been generated. Once previous efforts have been reviewed, the vocational rehabilitation agency can focus its efforts on remaining information gaps. Pooling staff and dollar resources for a statewide developmental disabilities needs assessment study may also be productive. The National Association of Developmental Disabilities Councils recently completed a national survey of consumers with developmental disabilities, and needs assessors should seriously consider it in relation to their own efforts as it may provide a solid foundation for other state studies.
4. Individuals with developmental disabilities usually have a significant impairment in their ability to read and or understand written correspondence. This can make written surveys ineffective in identifying their needs. Several alternatives to sending written surveys to this population that can be used (although each of them has its own sets of limitations) are face-to-face personal interviews, telephone interviews, and use of focus groups to identify and discuss needs.
5. When conducting interviews, the type of interview used is dependent on the purpose for which the interviews are held. Personal interviews and focus group sessions are useful when the purpose is to obtain information on the needs of a particular grouping of individuals or on a particular topic such as work conditions, housing arrangements, social interests or activities, and common medical needs.
6. Telephone interviewing is an alternative method for conducting general surveys such as prevalence studies. It has an advantage over written surveys in that the surveyor is able to clarify questions and relate to respondents in warmer and more personal ways, which should reflect on the return rate of acceptable surveys.

#### **Suggested Sources of Information on Needs of Persons with Developmental Disabilities**

#### **Organizations and Associations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of the developmentally disabled. They may be of

help for identifying service providers and key informants for the developmentally disabled. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

Administration on Developmental Disabilities (ADD), Office of Human Development Services, U.S. Department of Health and Human Services, Room 348F, HHH Building, 200 Independence Ave., SW, Washington, DC 20201, (202) 245-2890.

American Association of University Affiliated Programs for Persons With Developmental Disabilities (AAUAP), 8605 Cameron St., Suite 406, Silver Spring, MD 20910, (301) 588-8252.

Association for Retarded Citizen of the United States, National Headquarters, 2501 Avenue J, Arlington, TX 76006, (817) 640-0204.

National Association of Developmental Disability Councils, 1234 Massachusetts Avenue NW, Suite 103, Washington, DC 20005, (202) 347-1234.

National Association of State Mental Retardation Program Directors (NASMRPD), 113 Oronoco Street, Alexandria, VA 20025, (703) 683-4202.

National Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD 20785, (301) 459-3700.

National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), National Institutes of Health, U.S. Department of Health and Human Services, Building 31, Room 8A-16, Bethesda, MD 20892. (301) 496-5751.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave. SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitation Services, U.S. Department of Education, Switzer Building, 330 C Street SW, Washington, DC 20202, (202) 732-1282

The Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way, NE, Seattle, WA 98115, (206) 523-8446 or 1511 King

Street, Alexandria, VA 22314, (703) 683-5586.

United Cerebral Palsy Associations (UCP), 1522 K Street, Suite 1112, Washington, DC 20005, (202) 842-1266.

State and county developmental disabilities council and state and local advocacy groups working on behalf of citizens with mental retardation, epilepsy, and cerebral palsy can help identify service providers and key informants who know about the needs of persons with developmental disabilities. In addition, they usually can provide some prevalence, incidence, social indicator, and demographic data about this group.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

Residential programs and nursing homes can also be used as resources.

### **Research Centers and Research Projects**

Rehabilitation Research and Training Center for Improving the Community Integration for Persons with Mental Retardation, University of Minnesota, Department of Educational Psychology, 150 Pillsbury Drive SE, Minneapolis, MN, 55455. Robert Bruininks, Ph.D., Project Director, (612) 624-5720.

Rehabilitation Research and Training Center on Improving Supported Employment Outcomes for Individuals with Developmental and Other Severe Disabilities, Virginia Commonwealth University, School of Education, MCV Box 568, Richmond, VA 23284. Paul Wehman, Ph.D., Project Director, (804) 257-1851.

Rehabilitation Research and Training Center on Community Integration Resource Support, Syracuse University, Center on Human Policy, 724 Comstock Avenue, Syracuse, NY 13244-4230. Steven J. Taylor, Ph.D., Project Director, (315) 443-4484.

Rehabilitation Research and Training Center on Community Living, University of Minnesota, 101 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. Robert H. Bruininks, Ph.D., Project Director, (612) 625-3396.

Rehabilitation Research and Training Center for Community-Referenced Technologies for Nonaversive Behavior Modification, University of Oregon, Center on Human Development, 135 Education Building, Eugene, OR 97403. Robert H. Horner, Ph.D., Project

Director, (503) 686-5311.

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### Standard Resources for Assistance

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with developmental disabilities. These can include associations of parents, support groups, residential care providers, and local councils.

The Research and Training Centers with missions related to this population's needs, as identified above.

Universities and colleges with programs concerned with habilitation and rehabilitation of adults and special education programs. Especially useful are those with staff conducting research and development of facility, community, and institutional programs for severely developmentally disabled persons.

University Affiliated Facility Programs are funded by the Administration for Developmental Disabilities at universities throughout the United States. Many of these programs work quite effectively with state developmental disabilities councils to study problems and needs of persons with disabilities that are classified as developmental, rather than acquired, though the difference is not

always clear (e.g., some states include traumatic brain injury as developmental). The programs in a given state can be found by contacting either the Administration for Developmental Disabilities or the American Association of University Affiliated Programs for Persons With Developmental Disabilities (both listed above).

# *Chapter 7*

## **Specific Learning Disabilities**

### **Background and Discussion**

Needs assessment of persons with specific learning disabilities is a major challenge due to the complexity and variable characteristics of this disability. Specific learning disabilities has been defined as a disorder in one or more of the central nervous system processes involved in perceiving, understanding, and/or using concepts through verbal (spoken or written) language or nonverbal means.

Since this disability primarily affects the person's ability to communicate, special adjustments in any needs assessment methods will be required if the unique visual, auditory, motor, tactile, and academic functional limitations are to be accommodated. Specific learning disabilities manifest themselves with deficits in one or more of the following areas: attention, reasoning, processing, memory, communication, reading, writing, spelling, calculation, coordination, social competence, and emotional maturity (Rehabilitation Services Administration, 1985).

Hoffman, Sheldon, Minskoff, Sautter, Steidle, Baker, Bailey, and Echols (1987) surveyed adults with specific learning disabilities, providers of services, and consumer-advocates regarding their perceptions of the needs of persons with specific learning disabilities in the following areas: (a) academics, (b) medical and health, (c) vocational, (d) daily living skills, (e) social skills, and (f) personal adjustment. No major medical or health problems were identified or correlated with specific learning disabilities, and no major daily living skills deficits were noted with the exception of handling money. Instrument designs and methods for obtaining needs information from individuals must take into account how these specific disabilities may affect the assessment process.

**Academic Skills.** Results of their study indicated that adults with specific learning disabilities have significant academic problems with reading, spelling, arithmetic, and writing. Consequently, addressing their academic skill needs would involve training to develop academic skills required for employment, training to handle money, use bank services, complete a job application, and training in strategies to improve memory. Academic perceptual problems may include difficulty reading (dyslexia), writing (dysgraphia), and performing arithmetic (dyscalculia) (President's Commission, 1986). Needs assessment methods relying on surveys or discrimination between numbers on different survey scales may pose difficulties for persons having these functional limitations.

**Social Skills and Personal Adjustment.** Hoffman et al. (1987) also identified deficits in social skills including impulsive social behaviors,

independence, friendships, and conversation. Consequently, social skills training is suggested for some persons with specific learning disabilities to assist them in controlling impulsive behaviors, and to promote independence, friendships, and conversation. Personal adjustment deficits they identified included feelings of frustration, low self-confidence or self-concept, and depression. Suggestions for meeting these needs include developing support groups and counseling, or providing vocational or career education, jobs, and job training especially for those persons having difficulty maintaining a job.

**Perceptual Problems.** Visual perceptual problems include difficulty in receiving or in processing information by sight. For example, individuals with visual perceptual problems may have (a) difficulty locating specific information in a text or list, (b) difficulty in the sequencing or seeing objects or letters in the correct order, and (c) difficulty discriminating between similar letters like "u" and "v." Consequently, needs assessment methods utilizing written surveys or the ability to read and perform math might pose barriers to these persons (President's Committee on Employment of the Handicapped, 1986).

**Auditory Problems.** Persons with auditory problems may have difficulty in receiving accurate information through hearing. Such problems include (a) difficulty in hearing one sound over a background noise such as hearing another person's voice over a background of machinery noise, (b) difficulty in discriminating between similar sounds like "eighteen" and "eighty," (c) difficulty in the correct sequence of hearing sounds where the word "street" may sound like "treats," and (d) difficulty in following a sequence of instructions. Personal interview or telephone survey needs assessment methods should take into consideration these potential limitations.

**Motor Skills.** Persons with motor and tactile perceptual problems may have difficulty in fine and gross motor skills and may, therefore, appear clumsy. Tactile limitations may be manifested in not wanting to be touched by another person or discriminating between two objects by touch. Generally, these motor and tactile perceptual problems should not impact upon needs assessment methods with the exception of persons who have difficulty writing in completing the survey.

### Special Considerations in Assessing the Needs of Persons with Specific Learning Disabilities

Some of the considerations and accommodations that should be made in conducting needs assessments with persons with specific learning disabilities include the following:

1. Provide tapes instead of printed materials for persons having academic perceptual problems.

2. Provide a quiet environment when giving verbal instructions for persons having auditory perceptual problems.
3. Provide additional time to complete a task for persons with auditory and visual deficits.
4. Allow opportunity for the person to ask questions during the needs assessment and respond with clear and simple instructions for completing written surveys and/or telephone surveys.
5. Determine whether the person prefers or needs to have information (e.g., orally, written, or both) prior to the needs assessment.
6. Speak directly, clearly, and simply to the person.

**Suggested Sources of Information on the Needs  
of Persons with Specific Learning Disabilities**

**Organizations and Associations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation needs of the specific learning disabilities. They may be of help for identifying service providers and key informants for specific learning disabilities. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

Foundation for Children with Learning Disabilities (FCLD), P.O. Box 2929, Grand Central Station, New York, NY 10163, (212) 687-7211.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Network of Learning Disabled Adults (NNLDA), P.O. Box 716, Bryn Mawr, PA 19010, (215) 275-7211.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

Special education and other association journals and the bibliographies

prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

## Research Centers and Projects

Research and Training Center for Access to Rehabilitation and Economic Opportunity, Howard University, School of Education, 2900 Van Ness St. SW, Washington, DC 20059. Sylvia Walker, Ed.D., Project Director, (202) 686-6726.

Interamerica Research Association, 1555 Wilson Blvd. #600, Arlington, VA 22209, (703) 522-3332. Delores M. John, Ph.D., Project Director, "Research and demonstration project to improve functioning in families with learning disabled children."

University of Kansas, Institute for Research in Learning Disabilities, 206 Carruth O'Leary Hall, Lawrence, KS 66045, (913) 864-4780. J. Stephen Hazel, Ph.D., Project Director, "The development and evaluation of an intervention program for families with learning disabled youths."

## Selected Bibliography

Association for Children and Adults with Learning Disabilities. (1982 September/October). ACLD vocational committee survey of learning disabled adults: Preliminary report. ACLD Newsbriefs, pp 10-13.

Haig, J. H., & Patterson, B. H. (1980). An overview of adult learning disabilities. Paper presented at the annual meeting of the 13th Western College Reading Association, San Francisco.

Hoffman, F. J., Sheldon, K. L., Minskoff, E. H., Sautter, S. W., Steidle, E. F., Baker, D. P., Bailey, M. B., & Echols, L. D. (1987). Needs of learning disabled adults. Journal of Learning Disabilities, 20(1), 43-52.

Kaufman, J. M. (1985). Characteristics of childrens' behavior disorders. Columbus, OH: Charles E. Merrill.

National Joint Committee on Learning Disabilities. (1987). Adults with learning disabilities: A call to action. Learning Disabilities Quarterly, 9, 164-167.

Polloway, E. E., Smith, J. D., & Patton, J. R. (1984). Learning disabilities: An adult development perspective. Journal of Learning Disabilities, 7, 179-186.

P.L. 94-142. (1985). Education for All Handicapped Children Act of 1975, P.L. 94-142, 89, Stat. 773. Washington, DC: Government Printing.

President's Committee on Employment of the Handicapped. (1986). Supervising Adults with Learning Disabilities. Washington, DC: U.S. Government Printing Office.

Rehabilitation Services Administration. (January, 1985). Program Policy Directive (RSA-PPD-85-3), Washington, DC: Government Printing.

Taylor, H., Kaygag, M. R., & Leichenko, S. (1989). The ICD Survey III: A report card on special education. New York: Louis Harris and Associates.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of children and adults with learning disabilities.

Special education units at the state department or division of elementary and secondary education.

Rehabilitation Research and Training Centers with missions related to specific learning disabilities and developmental disabilities.

Organizations and universities conducting research and demonstration programs on learning disabilities through U.S. Department of Education grants and projects.

Universities and colleges with programs in special education and rehabilitation, especially those conducting research on learning, cognition, and learning disabilities. Also, do not overlook those schools that also sponsor adult literacy programs.

# *Chapter 8*

## **Traumatic Brain Injury**

### **Background and Discussion**

The population of persons with traumatic brain injury is estimated by the National Head Injury Foundation to be about 25,000,000 people and growing (UW-Stout RRTC, 1988). Therefore, it is identified as a significant segment of the population of individuals with handicaps and deserves special consideration in statewide rehabilitation needs assessment studies. State vocational rehabilitation agencies are required in their State Plan for vocational rehabilitation services to conduct statewide studies to determine the relative needs for vocational rehabilitation services of different significant segments of the states population of individuals with handicaps, including their need for rehabilitation facility services.

Traumatic brain injuries are among the most idiosyncratic of disabilities. A common characteristic of severe brain injury is that the injury produces diffuse and unpredictable damage to brain functions, along with any physical damage that may have occurred with the injury. Brain injury may affect motoric, cognitive, memory, and sensory capabilities, any of which may be exacerbated by medication or other coincident losses of function. These specific impacts of the disability will influence an individual's capacities to relate to instruments in the needs assessment process.

**Physical Limitations.** Paralysis, weakness, ataxia, hemiparesis and altered handedness, diminished coordination, poor dexterity, and other residual physical effects may make it difficult for persons with traumatic brain injury to physically complete written surveys.

**Language and Communication Difficulties.** Persons with aphasia may have limited ability to respond to written and verbal surveys, and responses in these cases may not always make sense. Communication difficulties, such as dysarthria (difficulty in speaking), may limit ability to respond to certain types of surveys (i.e., verbal interviews). Questions involving sequential responses may not be appropriate and may not yield significant information.

**Visual Impairments.** Field cuts, diplopia (double vision), and other visual impairments may also limit one's ability to respond to written surveys. Taped questions and large print version of questions may be necessary.

**Medication Side Effects.** Neuroleptic medications used to treat seizures and other medications may cause blurred vision, tremors, and difficulty with dexterity.

**Cognitive Deficits.** Common deficits such as problems with comprehension, attention, and concentration may lead to difficulty when completing surveys. Information may need to be simplified and made concrete in nature. Persons with traumatic brain injury typically do not respond well to open-ended types of questions for a variety of reasons. In some cases, family, friends or helping professionals may be the best source for useful information in these cases or may be needed to assist in two-way communication with the individual.

**Memory Deficits.** Persons with traumatic brain injury are often unable to provide accurate background information. Remote memory may be intact, but they may be unable to consolidate, store, and recall new information over time and may be unable to provide accurate information about the activities in which they are currently involved. For example, they may forget to report that they are in any rehabilitation programs. Further, they may be unable to provide such details as dates, names of service providers, hospitalizations, therapies, and treatment. Persons with traumatic brain injury may forget appointments, dates to return surveys by, or previous contacts or conversations with surveyors.

In some cases, these memory deficits may diminish reliable results and it may be necessary to obtain verification from others familiar with the impact of their disabilities. Family members or service providers may provide responses substantially different from those of a brain injured subject because of his or her memory and perception problems. This duplication of effort or the use of alternative assessment methods can more than double the process time, with a similar impact on the assessment budget and other resources.

**Executive Function Difficulties.** Persons with traumatic brain injury may have difficulty in initiating and completing activities and may, therefore, have difficulty in completing surveys, returning forms, or returning phone calls.

**Difficulty Acknowledging Deficits.** Persons with traumatic brain injury may be poor judges of their strengths, limitations, and deficits. Their focus may be on their physical deficits or other obvious problems, and they may not mention the cause of the deficit. For instance, they may report that their right side is weak, that they have seizures, or that their balance is not very good but will not indicate that they have sustained a head injury. As a result, their perceptions of their capabilities and service needs may be inaccurate.

**Premorbid Personality.** Persons with traumatic brain injury are not representative of the general population in that as a group they are often young, male, and have histories of chemical dependency, risk-taking, and antisocial personality characteristics. Some of the considerations of needs and ways to estimate needs among youth in transition will also apply in the case of the young head injured person.

**Stigma and Blame.** Stigma attached to "brain damage" often leads persons with traumatic brain injury to be reluctant to attribute their problems to traumatic brain injury or head injury. In addition, persons with traumatic brain injury may also have a tendency to "blame" their difficulties on others or the "system" rather than acknowledge the actual deficits and problems they experience. It may be necessary to question indirectly about need, asking questions of fact, rather than interpretation.

### **Special Considerations in Assessing the Needs of Persons with Traumatic Brain Injury**

1. When surveys and interviews are to be used with individuals with brain trauma, alternate formats typically used with persons with physical and sensory disabilities (e.g., cardboard questionnaires, large type, audio-taped questions) may be required.
2. Questionnaires should be constructed to simply solicit data on factual and functional consequences of the brain injury, rather than gathering data from interpretive items. For instance, asking "Have you ever been unconscious for a period of time, and if so, for how long and what was the cause?" is more likely to get data on need than asking "Have you had any serious impairments as a result of a head injury?"
3. It may be necessary to route survey and appointment information through family members or significant others, in addition to the individual, to ensure the client's participation and follow-through.
4. In some cases, difficulty in eliciting reliable data from the head-injured person may require verification by others. Family members or service providers may provide substantially different responses than a brain-injured subject would because of his or her memory and perception problems.
5. Use of multiple perspectives on need (e.g., individual, family, professional) may yield a more accurate estimate of need, but these multiple assessment methods can more than double the cost and use of other resources in the assessment.
6. Support groups for head-injury victims and their families, sponsored by state chapters of the National Head Injury Foundation, are becoming much more common. These groups may be a useful source for conducting focus groups to identify needs from one or more perspective.
7. Specialized brain trauma rehabilitation hospitals and university treatment clinics may be helpful in providing general background information as well as assisting in the design of needs assessment instruments and procedures.

Some independent living centers may have developed special capacities to serve this population and may be interested in participating as co-sponsors of a needs assessment. The National Head Injury Association and some state chapters may already have basic background data on history and needs of the population.

8. An interagency approach that uses service providers in locating respondents is useful in assessing the needs of this population. For example, in Wisconsin a state Brain Injury Task Force, with the assistance of the UW-Stout Rehabilitation Research and Training Center, conducted a study using various service agencies to identify the needs and consequences of brain injury (see References). Approximately 900 surveys were returned by family members or significant others while 409 were returned by head-injured persons themselves.

#### **Suggested Sources of Information on Needs of Persons with Traumatic Brain Injury**

#### **Organizations and Associations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of persons with traumatic brain injuries. They may be of help for identifying service providers and key informants for persons with traumatic brain injuries. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

Administration on Developmental Disabilities (ADD), Office of Human Development Services, U.S. Department of Health and Human Services, Room 348F, HHH Building, 200 Independence Ave., SW, Washington, DC 20201, (202) 245-2890.

National Institute of Neurological and Communicative Disorders and Stroke (NINCDS), National Institutes of Health, U.S. Department of Health and Human Services, Building 31, Room 8A-16, Bethesda, MD 20892, (301) 496-5751.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Head Injury Foundation, 330 Turnpike Road, Southboro, MA 01772, (508) 485-9950.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

Traumatic Brain Injury Research/Education Association (TBI Association), 25432 Seventh, Grosse Ile, MI 48138, (313) 671-8366. Developmental disabilities boards in states where head injury is classified for funding purposes as a cognitive disability, state departments of transportation where fees or fines are used to fund or supplement costs for rehabilitation (e.g., Florida)

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

### **Research Centers, Regional Centers, and Projects**

Rehabilitation Research and Training Center for Community Integration of Persons With Traumatic Brain Injury, State University of New York at Buffalo, 197 Farber Hall, 3435 Main Street, Buffalo, NY 14214. John H. Noble, Jr., Ph.D., Project Director, (716) 636-2300.

Rehabilitation Research and Training Center in Traumatic Brain Injury, University of Washington, Department of Rehabilitation Medicine, B-919 Health Sciences Building, Seattle, WA 98195. Justin F. Lehmann, M.D., Project Director, (206) 543-6766.

Rehabilitation Research and Training Center on New Directions for Rehabilitation Facilities, University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, School of Education and Human Services, Menomonie, WI 54751, Daniel C. McAlees, Ph.D., Project Director, (715) 232-1389.

Rehabilitation Research and Training Center in Traumatic Brain Injury, Virginia Commonwealth University, Medical College of Virginia, Box 434, MCV Station, Richmond, VA 23298-0434. Henry H. Sonnington, Project Director, (804) 786-0231.

Research and Training Center for Head Trauma and Stroke, New York University Medical Center, Department of Physical Medicine, 550 First Ave., New York, NY 10016. Leonard Diller, Ph.D., Project Director, (212) 340-6161.

Midwest Regional Head Injury Center for Rehabilitation and Prevention, Rehabilitation Institute of Chicago, 345 East Superior, Chicago, IL 60611. Henry B. Betts, M.D., Director, (312) 908-6017.

Rocky Mountain Regional Head Injury Center, Colorado Rehabilitation Services, Facilities Grants and Independent Living, 1575 Sherman Street, 4th Floor, Denver, CO 80203. Richard Parsons, Director, (303) 866-6024.

Southwest Regional Comprehensive Brain Injury Rehabilitation and Prevention Center, The Institute for Rehabilitation and Research, Brain Injury Program, 1333 Moursund Avenue, Houston, TX 77030. L. Don Lehmkuhl, Ph.D., Director, (713) 797-5713.

Comprehensive Regional Traumatic Brain Injury Rehabilitation and Prevention Center, Mount Sinai Medical Center, One Gustave Levy Place, New York, NY 10029. Wayne A. Gordon, Ph.D., Director, (212) 241-7917.

"Development, implementation, and validation of supported employment model(s) for traumatically brain injured populations," University of Wisconsin-Stout, Research and Training Center, Menomonie, WI 54751. Dale Thomas, Project Director, (715) 232-2236.

"A comprehensive system of care for traumatic, brain injury," Institute for Medical Research, Santa Clara County, 2260 Clove Street, San Jose, CA 95128. Jeffrey Englander, M.D., Project Director, (408) 257-7538.

"A model system for minimizing disabilities after head injury," Institute for Rehabilitation and Research, 1333 Moursund Avenue, Houston, TX 77030. Catherine Bantke, M.D., Project Director, (713) 799-7011.

"Supported employment for persons with traumatic brain injury," Minnesota Department of Jobs and Training, Division of Rehabilitation Services, 390 N. Robert Street, 5th Floor, St. Paul, MN 55101. Mary Shortall, Project Director, (612) 296-0219.

"Model project for comprehensive rehabilitation services to individuals with traumatic brain injury," Mt. Sinai Medical Center, School of Medicine, One Gustave L. Levy Place, New York, NY 10029. Kristjan Ragnarsson, M.D., Project Director, (212) 650-6335.

"A comprehensive model of research and rehabilitation for the traumatically brain injured," Virginia Commonwealth University,

Medical College of Virginia, Box 568 MCV Station, Richmond, VA 23298. Jeffrey Kreutzer, Ph.D., Project Director, (804) 785-0200.

"South Eastern Michigan traumatic brain injury system," Wayne State University, Department of Neurology, Detroit, MI 48202. Mitch Rosenthal, Ph.D., Project Director, (202) 732-1192.

"Supported employment in traumatic brain injury," Wisconsin Department of Health, Division of Vocational Rehabilitation, P.O. Box 7852, Madison, WI 53707. Sue Kidder, Project Director, (608) 266-3729.

Rehabilitation Engineering Center on Modifications to Worksites and Educational Settings, Cerebral Palsy Research Foundation of Kansas, Inc., 2021 North Old Manor, Box 8217, Wichita, KS 67208. John H. Leslie, Ph.D., Project Director, (316) 688-1888.

Rehabilitation Engineering Center on the Quantification of Human Performance, Massachusetts Institute of Technology, Harvard-MIT Rehabilitation Engineering Center, 77 Massachusetts Avenue, Cambridge, MA 02139. Robert W. Mann, SC.D., Project Director, (617) 253-0460.

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Aronow, A. U. (1987). Rehabilitation effectiveness with severe brain injury: Translating research into policy. Journal of Head Trauma Rehabilitation, 2(3), 24-36.

Ayers, D. K., & Norris, C. M. (1985). Transitional employment model for adults with brain injuries. American Archives of Rehabilitation Therapy, 33(3).

Berrol, S., & Rosenthal, M. (Eds.). (1987). Educational, vocational and social integration. Special Edition. Journal of Head Trauma Rehabilitation, 2(1).

Corthell, D. (Ed.). (1990). Traumatic brain injury and vocational rehabilitation. Menomonie: University of Wisconsin-Stout, Research and Training Center.

Diller, L., & Ben-Yishay, Y. (1983). "Severe head trauma: A comprehensive medical approach to rehabilitation." New York: New York University Rehabilitation Research and Training Center.

Edelstein, B. A., & Couture, E. T. (Eds.) (1984). Behavioral assessment and rehabilitation of the traumatically brain-damaged. New York: Plenum Press.

Finger, S. (Ed.) (1978). Recovery from brain damage: Research and theory. New York: Plenum Press.

Goldstein, G. (1983). Rehabilitation of the brain-damaged adult. New York: Plenum Press.

Institute on Rehabilitation Issues (IRI). (1986). Traumatic brain injury. Menomonie, WI: Research and Training Center, University of Wisconsin-Stout.

Johnson, J. R., & Higgins, L. (1987). Integration of family dynamics into the rehabilitation of the brain-injured patient. Rehabilitation Nursing, 12(6), 320-322.

Kay, T., & Silver, S. (1988). The contribution of the neuropsychological evaluation to the vocational rehabilitation of the head-injured adult. Journal of Head Trauma Rehabilitation, 3(1), 65-77.

Menz, F. E., & Thomas, D. F. (1990). Unresolved issues in the rehabilitation and community-based employment of persons with traumatic brain injury. In D. Corthell (Ed.), Traumatic brain injury and vocational rehabilitation (pp. 225-247). Menomonie, WI: University of Wisconsin-Stout, Research and Training Center.

Thomas, D. F. (1990). Vocational evaluation of persons with traumatic head injury. In D. Corthell (Ed.), Traumatic brain injury and vocational rehabilitation (pp. 111-139). Menomonie, WI: University of Wisconsin-Stout, Research and Training Center.

Thomas, D. F. (1989). Vocational evaluation of people with traumatic brain injury. Vocational Evaluation and Work Adjustment Bulletin, 22(2).

Thomas, D. F., & Czerlinsky, T. (1987). Wisconsin survey of traumatic head injuries: An assessment of rehabilitation needs and social, economic, and personal loss: A preliminary report. Menomonie, WI: Research and Training Center, University of Wisconsin-Stout.

Thomas, D. F., & Menz, F. E. (1990). Conclusions of a national think tank on issues relevant to community-based employment for survivors of traumatic brain injury. American Rehabilitation, 16(2), 20-24.

Thomas, D. F., Menz, F. E., & McAlees, D. (Eds.). (In press). Community-based employment following traumatic brain injury. Menomonie: University of Wisconsin-Stout, Research and Training Center.

Wagner, A. L. (1988). An investigation of supported work programs with

persons with traumatic brain injuries (TBI). Unpublished master's thesis, University of Wisconsin-Stout, Menomonie, WI.

Wisconsin Department of Health and Social Services. (1988). Department of Health and Social Services Brain Injury Task Force Final Report to the Secretary. Madison, WI: Author.

### **Standard Resources for Assistance**

State chapters of the National Head Injury Foundation and local support groups for victims and their families.

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with head injury.

The Research and Training Centers and demonstration projects with mission areas in the area of inquiry listed above.

Universities and colleges with medical and rehabilitation programs concerned with brain injury and other programs that teach and conduct research on the unique needs of this population.

Acute care medical facilities, especially those attached to teaching and research hospitals, that maintain registries and records on trauma and brain injury.

# *Chapter 9*

## **Blindness and Visual Impairments**

### **Background and Discussion**

Federal regulations require state vocational rehabilitation agencies to "Determine the relative need for vocational rehabilitation services for the different segments of the population of individuals with handicaps" including the needs of individuals with severe visual handicaps.

Sight is the sense by which people process 80 percent of the information they obtain. The loss of sight, thus, has a major impact on a person's ability to quickly and efficiently obtain information from their environment to help them understand the world around them. As a result a person who is blind has several unique needs that other types of disability groups do not have, which also must be assessed.

### **Special Considerations in Assessing the Needs of Persons with Blindness and Visual Impairments**

1. As with any other population, it is important to determine the scope of needs to be assessed by the study with this populations. In the case of blindness and visual impairment, it should be remembered that this disability impacts all aspects of a person's life. Where there is a state agency for the blind that agency is likely to provide services that are normally beyond the scope of a general rehabilitation agency.
2. Questions addressing the prevalence of the following specific needs should be built into the state agency's assessment:
  - a. Alternative or compensatory skill training
  - b. Low vision aids or equipment
  - c. Braille training
  - d. Mobility and travel training
  - e. Cooking skills
  - f. Homemaking skills
3. As with other severely disabled populations, it is important that the independent living needs of visually impaired people be assessed.
4. Telephone and personal interviews are likely to be most appropriate with this population, due to their visual impairments.
5. Where Braille forms of surveys are used, it may also be useful to use taped instructions and taped versions of the survey instrument to facilitate detailed explanations and questions.

6. Persons with blindness and visual impairment are one of the most consistently documented disability populations in most states. These persons are identified for tax purposes. These records could be very useful for selecting a representative sample of the population for the assessment.
7. Advocacy organizations and rehabilitation facilities working with blind populations may be very useful resources for locating and enlisting the cooperation of blind individuals. They may also be interested in assisting in collecting data on needs as these data would also be helpful for improvement of their programs.

### **Suggested Sources of Information on Needs of Persons with Blindness and Visual Impairments**

#### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitaion service needs of the visually impaired. They may be of help for identifying service providers and key informants for the visually impaired. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

American Council of the Blind (ACB), Suite 1100, 1010 Vermont Ave., NW, Washington, DC 20005, (202) 393-3666, (800) 424-8666

American Foundation for the Blind, Inc. (AFB), 11615 M Street, NW, Washington, DC 20036, (202) 457-1487.

National Eye Institute (NEI), National Institutes of Health, U.S. Department of Health and Human Services, Building 31, Room 6A32, Bethesda, MD 20892, (301) 496-5248

National Industries for the Blind (NIB), Rehabilitation Services Division, 524 Hamburg Turnpike, Wayne, NJ 07470, (201) 595-9200

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-

1294.

Rehabilitation facilities specializing in blind populations or who serve significant numbers of blind persons.

State and regional rehabilitation programs with specific program responsibilities. Not to be overlooked are counselors at agencies (general or blind) with blind caseloads in own or another state.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

### **Research Centers and Projects**

Rehabilitation Research and Training Center on Blindness and Low Vision Rehabilitation, Mississippi State University, P.O. Box 5365, Mississippi State, MS 39762. William H. Graves, Ph.D., Project Director, (601) 325-2001.

Rehabilitation Engineering Center on Development and Evaluation of Sensory Aids for Blind and Deaf, Smith-Kettlewell Institute of Visual Sciences, 2232 Webster Street, San Francisco, CA 94115. Arthur Jampolsky, M.D., Project Director, (415) 561-1630.

Rehabilitation Engineering Center on Augmentative Communication Devices, University of Delaware, Department of Computer and Information Science, Newark, DE 19711. Richard Foulds, Ph.D., Project Director, (302) 451-2712.

"Assessing and addressing the needs of the blind and visually impaired population on the Hopi Reservation," American Foundation for the Blind, Social Research, 15 W. 16th Street, New York, NY 10011. Eva Friedlander, Project Director, (212) 620-2145.

"Orientation and mobility for blind adults over 60 years of age: Development of an instrument to assess the mobility needs of visually impaired persons over 60 years of age," Vanderbilt University, Peabody College, Room 512, Kirkland Hall, Nashville, TN 37240. Randall Harley, Ph.D., Project Director, (615) 322-8160.

### **Selected Bibliography**

Dobree, J. H. (1982). Blindness and visual handicap: The facts. Oxford, NY: Oxford University Press.

Ellis, D. (Ed.) (1986). Sensory impairments in mentally handicapped people. San Diego, CA: College-Hill Press.

Lowenfeld, B. (1981). Berthold Lowenfeld on blindness and blind people: Selected papers. New York: American Foundation for the Blind.

Resources for Rehabilitation. (1989). Providing services for people with vision loss: A multidisciplinary perspective. Lexington, MA: Author.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with limited sight.

The Research and Training Center with a mission areas in this area of disability.

Universities and colleges with programs concerned with blindness, mobility training, and other programs which teach and conduct research on the unique problems differences and disabilities of this population. Not to be overlooked are rehabilitation programs at area or state colleges and universities.

# *Chapter 10*

## **Deafness**

### **Background and Discussion**

State vocational rehabilitation agencies are required by Regulations for State Plan for Vocational Rehabilitation Services (U.S. Department of Education, Section 8.1, May 12, 1988) to conduct statewide studies to determine the relative needs for vocational rehabilitation services of different significant segments of the state's population of individuals with handicaps, including the need for rehabilitation facility services. However, there is no specific reference to needs assessment for persons with hearing impairments in the Rehabilitation Act.

The population of persons with hearing impairments, in the United States, who are limited in their capacity to work is estimated by the National Health Interview Survey at 425,000 (La Plante, 1988, pp. 77, 80). The last major national census of the hearing impaired population was conducted by the National Association of the Deaf in 1971 and revealed the prevalence rates (Schein & Delk, 1974, p. 16) displayed on the following table:

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Degree of Impairment	Total Counts	Rates Per 100,000
All Hearing Impaired	13,362,842	6,603
Significant Bilaterally Impaired	6,548,842	3,236
Deafness	1,767,046	873
Prevocational (under 19)	410,522	203
Prelingual (under 3)	201,626	100

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While the numbers of individuals with deafness may not be so great as other rehabilitation target groups (e.g., such as those with physical disabilities), special considerations are necessary when conducting studies of their rehabilitation needs. Special considerations will be required in design of the studies due to definitional differences as to what constitutes a significant impairment, communication modes and reading skills of individuals, and problems in gaining cooperation and participation in the assessment.

## Definitions and Extent of Impairment

Definitions used for basing sample selection will affect results of the assessed needs. Hearing impairments and deafness are typically classified in one or more of three ways: (a) by audiometric examination, (b) by self-report against functional criteria (e.g., can understand spoken language if sees the person's lips), and (c) by age of onset. Age of onset has been adopted as a criterion because the earlier onset of hearing impairment, the more difficulty there is for language acquisition. In turn, age has implications for an individual's preferred communication mode and the types of services or rehabilitation resources he/she might require to become able to communicate. The assessment results will be dependent on the classification system used and on the degree of impairment that is considered in the assessment. Quite different needs will be identified among a sample whose age of onset was during adolescence and who had minimal impairment as compared to needs among a sample that includes persons with total hearing losses that occurred earlier in their developmental history.

## Communication Modes and Reading Skills

Individuals with hearing impairments may rely on varying combinations of sign language modalities, lipreading, or written communication. Interviews should be conducted using appropriately certified interpreters. Further, it may be necessary to spend some time prior to an interview, group discussion or public forum to identify and "tune in" to the person's preferred method of communication. Any telephone surveys of the disabled population must allow for use of telecommunication devices (TDDs).

Many persons with hearing impairments, especially those whose impairment was prelingual, will likely have limited reading skills. The use of written questionnaires may not be appropriate with this population. If instructions or the assessment instruments are in written form, attention must be given to keeping the reading level and complexity of questions to a minimum.

## Locating Hearing Impaired Persons

Locating appropriate representatives of the hearing impaired population may be difficult. This is a relatively hidden disability, and therefore, special sampling techniques may be required in order to locate the population for assessment. Schein and Delk (1974) reported that the 1971 National Census of the Deaf Population relied on lists of known deaf individuals supplied by literally thousands of agencies and organizations. This approach was compared to and supplemented by a general population sample.

## **Logistics for Conducting the Assessment**

Advocacy groups in the "deaf community" can be an important source of assistance for announcing and aiding in the needs assessment. It is important that there be sufficient notice of these opportunities for input into rehabilitation planning, especially when public forums and meetings will be used. Skilled sign language interpreters must be available at all meetings where hearing impaired individuals are in attendance. This involves a fair amount of scheduling and will add cost to the needs assessment. Such notification is also important in that these advocates may also be helpful in publicizing any impending surveys that would be conducted.

Close collaboration with both experts in deafness and representatives of the deaf community is critical to the success of needs assessment with this population. Due to the varying communication needs of hearing persons, a combination of sampling techniques and survey modalities is suggested.

### **Suggested Sources of Information on Needs of Persons Who are Deaf**

#### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the needs of the hearing impaired. They may be of help for identifying service providers and key informants for the hearing impaired. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

American Deafness and Rehabilitation Association (ADARA), 814 Thayer Ave., Silver Spring, MD 20910, (301) 589-0880 (VOICE/TDD).

American Speech-Language-Hearing Association (ASHA), 10801 Rockville Pike, Rockville, MD 20852, (301) 897-5700 (VOICE/TDD).

National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910, (301) 587-1788.

National Council on Communicative Disorders (NCCD), 10801 Rockville Pike, Rockville, MD 20852, (301) 493-4914.

National Information Center on Deafness, Gallaudet College, 800 Florida Ave., NE, Washington, DC 20002, (202) 651-5109 (VOICE), (202) 651-5976 (TDD).

National Institute of Neurological and Communicative Disorders and

Stroke (NINCDS), National Institutes of Health, U.S. Department of Health and Human Services, Building 31, Room 8A-16, Bethesda, MD 20892, (301) 496-5751.

National Institute on Deafness and Other Communication Disorders, National Institute of Health and Human Services Dept., 9000 Rockville Pike, Bethesda, MD 20892, (301) 496-6596.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

National Technical Institute for the Deaf (NTID), Rochester Institute of Technology (RIT), One Lomb Memorial Drive, P.O. Box 9887, Rochester, NY 14623, (716) 475-6400 (VOICE), (716) 475-2181 (TDD).

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

State and regional rehabilitation programs with specific program responsibilities. Not to be overlooked are counselors at agencies with hearing impaired caseloads in own or another state.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

Schools for deaf adolescents and residential programs.

### **Research Centers and Projects**

Rehabilitation Research and Training Center on Deafness and Hearing Impairments, University of Arkansas, 4601 West Markham, Little Rock, AR 72205. Douglas Watson, Ph.D., Project Director, (501) 371-1654.

Rehabilitation Research and Training Center on Mental Health Rehabilitation of Individuals With Deafness, University of California-San Francisco, Center for Deafness, 3333 California Street, Suite 10,

San Francisco, CA 94143. Mimi W. P. Lou, Ph.D., Acting Director/Training Director, (415) 476-4980.

"Transition from school to work for deaf youth," Gallaudet College, Gallaudet Research Institute, 800 Florida Ave., NE, Washington, DC 20002. Judith Harkins, Project Director, (202) 651-5400.

"Transition study of persons who are hard of hearing, deaf, or hearing impaired with secondary handicapping conditions," Oregon State System of Higher Education, Teaching Research Division, 345 N. Monmouth Ave., Monmouth, OR 97361. Michael Bullis, Ph.D., Project Director, (503) 838-1220.

"Transition from school to work for deaf youth," University of Arkansas, Fayetteville, AR 72701. Douglas Watson, Ph.D., Project Director, (501) 371-1654.

Rehabilitation Engineering Center on Development and Evaluation of Sensory Aids for Blind and Deaf, Smith-Kettlewell Institute of Visual Sciences, 2232 Webster Street, San Francisco, CA 94115. Arthur Jampolsky, M.D., Project Director, (415) 561-1630.

Rehabilitation Engineering Center on Technological Aids for Deaf and Hearing Impaired Individuals, The Lexington Center, Incorporated, Research and Training Division, 30th and 75th Street, Jackson Heights, NY 11370. Harry Levitt, Project Director, (718) 899-8800, extension 230.

## Selected Bibliography

Anderson, G. B., & Watson, D. (Eds.) (1985). Counseling deaf people: Research and practice. Arkansas Rehabilitation Research and Training Center on Deafness and Hearing Impairment.

Bolton, B., & Thornton, L.,(Eds.). (1971). Critical needs in serving deaf rehabilitation clients in Region VI. Hot Springs, AR: University of Arkansas Rehabilitation Research and Training Center and Hot Springs Rehabilitation Center, AR.

Danek, M. M. (1987). Personnel shortages and practitioner competencies in deafness rehabilitation. American Rehabilitation, 13(3), 8-14.

Fairweather, B. C. (1983). Communication systems for severely handicapped persons. Springfield, IL: C. C. Thomas.

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Gasaway, D. C. (1985). Hearing conservation: A practical manual and guide. Englewood Cliffs, NJ: Prentice-Hall.

Institute for Information Studies. (1983). Vocational rehabilitation with hearing impaired clients. Rehab Brief, VI(10).

Jordan, I. K. (1988). Hearing impairment: The next ten years. The Hearing Journal, 41(10), 32-33.

La Plante, M. P. (1988). Data on disability from the National Health Interview Survey, 1983-85. An InfoUse Report. Washington, DC: National Institute on Disability and Rehabilitation Research.

Levine, E. S. (1981). The ecology of early deafness: Guides to fashioning environments and psychological assessments. New York: Columbia University Press.

Nespoulous, P. P., & Lecours, A. R. (Eds.). (1986). The biological foundation to gestures: Motor and semeiotic aspects. Hillsdale, NJ: L. Erlbaum Associates.

Powell, F. (Ed.). (1985). Education of the hearing impaired child. San Diego, CA: College-Hill Press.

Schein, J. D., & Delk, M. T. (1974). The deaf population of the United States. Silver Spring, MD: National Association of the Deaf.

Schwartz, A. H. (1984). The handbook of microcomputer applications in communication disorders. San Diego, CA: College-Hill Press.

Taylor, O. L. (Ed.). (1986). Nature of communication disorders in culturally and linguistically diverse populations. San Diego, CA: College-Hill Press.

Taylor, O. L. (Ed.). (1986). Treatment of communication disorders in culturally and linguistically diverse populations. San Diego, CA: College-Hill Press.

Wolf, E. G., Delk, M. T., & Schein, J. D. (1982). Needs assessment of services to deaf-blind individuals: Final report. Redex, MD.

**Standard Resources for Assistance**

American Annals of the Deaf. This is an education-oriented journal dealing with deaf issues.

The Journal of Rehabilitation of the Deaf is published by the American Deafness and Rehabilitation Association.

Community action, advocacy, religious, schools, and service delivery agencies and organizations working on behalf of persons with deafness. These may include associations of parents, support groups, residential care providers, and local facilities and may be quite helpful in conducting the needs assessment because of their high interest.

State and local councils for hearing impairment, university and private speech and hearing clinics, and state offices for deafness and communication disorders. Advocacy groups can be a valuable resource for enlisting cooperation with "deaf communities" and sometimes in carrying out data collection.

Research and Training Centers, colleges, and research projects with missions related to this population's needs, as identified above.

Universities and colleges with programs concerning habilitation and rehabilitation of persons with hearing impairments. Especially useful are those with communication disorders departments with staff conducting research and developing community and institutional alternatives for deaf individuals.

# *Chapter 11*

## **Youth in Transition**

### **Background and Discussion**

State Plans for vocational rehabilitation services require states to coordinate vocational rehabilitation services with educational programs so that handicapped youth, who are eligible for vocational rehabilitation services, will be able to make smooth transitions from school to employment and other related activities.

In addition, state vocational rehabilitation agencies should provide, as an attachment to their State Plans, descriptions of plans, policies, and methods related to the transition of handicapped youth. This description of past activities, accomplishments, and agency initiatives for the coming years should be based on the findings of a statewide assessment of needs for vocational rehabilitation services and the annual evaluation of state agency effectiveness.

State vocational rehabilitation agencies are also required to use data provided by state special education agencies under Section 618(b)(3) of the Education of the Handicapped Act in their assessment of needs for vocational rehabilitation services. Other useful resources for information and data are U.S. census reports, state and national health surveys, developmental disabilities agency reports and data, school counselors, and vocational rehabilitation counselors.

### **Special Considerations in Assessing the Needs of Youth with Disabilities**

Since this population is in the period of making a major transition from childhood to adulthood, at this time there are several considerations that they need that are not prevalent in other target populations.

1. Most of this population are minors still living at home. As a result, the needs assessment information obtained from parents may reflect parents' wishes rather than the needs of youth.
2. Since most of this population is vocationally immature, they lack knowledge of the world of work and where they fit into it. They likely do not know what they do not know. Questions may have to be more indirect to detect how their disability may affect their social or vocational functioning.
3. Since special education definitions of disability are not always the same as those used in rehabilitation, it may not be particularly useful to identify the types of vocational and independent living needs of these individuals in relation to the types of their disabilities.

4. Special education data is available, but these data are usually based on assessments from an academic perspective. They may be limited in terms of how useful that information is for assessing needs from a vocational or independent living perspective. They will, however, indicate prevalence and incidence of students reaching their transition period.
5. The scope of needs assessment for this population may need to be expanded to include the academic and "transition into adult life" adjustment needs of this population. This information may be provided to schools to help improve their emphasis on adult life transition programming as part of instructional programming.
6. In assessing this population's needs it may be useful to also use focus groups and public meetings to obtain the perspectives of informed parents, teachers, and advocates on the needs of this population.
7. If the information needed to assess the transition service needs of handicapped youth can be collected as a part of the state unit's comprehensive needs assessment study, special efforts may be needed to assure that handicapped youth are included in the study sample and that questions are carefully phrased for them.

#### **Suggested Sources of Information on Needs of Youth with Disabilities**

#### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of youth in transition. They may be of help for identifying service providers and key informants for the youth in transition. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

Administration on Developmental Disabilities (ADD), Office of Human Development Services, U.S. Department of Health and Human Services, Room 348F, HHH Building, 200 Independence Ave., SW, Washington, DC 20201, (202) 245-2890.

American Association of Psychiatric Services for Children (AAPSC), 1133 Fifteenth St., NW, Suite 1000, Washington, DC 20005, (202) 429-9713.

Association for Children and Adults with Learning Disabilities (ACLD), 4156 Library Road, Pittsburgh, PA 15234, (412) 341-1515, (412) 341-8077.

The Council for Exceptional Youth (CEC), 1920 Association Dr., Reston, VA 22091, (703) 620-3660.

Foundation for Children with Learning Disabilities (FCLD), P.O. Box 2929, Grand Central Station, New York, NY 10163, (212) 687-7211.

Junior National Association of the Deaf (JR. NAD), 445 N. Pennsylvania, Suite 804, Indianapolis, IN 46204, (317) 638-1715 (VOICE AND TDD).

National Association of Developmental Disability Councils, 1234 Massachusetts Avenue NW, Suite 103, Washington, DC 20005, (202) 347-1234.

National Information Center for Handicapped Children and Youth (NICHCY), Box 1492, Washington, DC 20013.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitation Services, U.S. Department of Education, Switzer Building, 330 C Street, SW, Washington, DC 20202, (202) 732-1282.

The Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way, NE, Seattle, WA 98115, (206) 523-8446 or 1511 King Street, Alexandria, VA 22314, (703) 683-5586.

United Cerebral Palsy Associations (UCP), 1522 K Street, Suite 1112, Washington, DC 20005, (202) 842-1266.

State and local councils on exceptional children; state and county developmental disabilities council; state and local advocacy groups working on behalf of youth with mental retardation, epilepsy, cerebral palsy, and physical disabilities. These organizations can help identify service providers and key informants who know about the needs of youth in transition. In addition, they usually can provide some prevalence, incidence, social indicator, and demographic data for this group.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

### **Research Centers and Projects**

**Rehabilitation Research and Training Center for Seriously Emotionally Handicapped Children and Their Families, Portland State University, Regional Research Institute, P.O. Box 751, Portland, OR 97207.** Barbara Frieson, Ph.D., Project Director, (503) 464-4040.

**Rehabilitation Research and Training Center in Rehabilitation and Childhood Trauma, Tufts-New England Medical Center, Department of Rehabilitation Medicine, 171 Harrison Ave., Boston, MA 02111.** Bruce Gans, M.D., Project Director, (617) 956-5622.

**Rehabilitation Research and Training Center for Improving the Community Integration for Persons with Mental Retardation, University of Minnesota, Department of Educational Psychology, 150 Pillsbury Drive SE, Minneapolis MN 55455.** Robert Bruininks, Ph.D., Project Director, (612) 624-5720.

**Rehabilitation Research and Training Center on Community Integration Resource Support, Syracuse University Center on Human Policy, 4E Huntington Hall, Syracuse, NY 13210.** Steven Taylor, Ph.D., Project Director, (315) 423-3851.

**Research and Training Center to Improve Services for Seriously Emotionally Ill Handicapped Children and Their Families, Portland State University, Regional Research Institute, P.O. Box 751,, Portland, OR 97207.** Barbara Friesen, Ph.D., Project Director, (503) 464-4040.

**Rehabilitation Research and Training Center on New Directions for Rehabilitation Facilities, University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, School of Education and Human Services, Menomonie, WI 54751.** Daniel C. McAlees, Ph.D., Project Director, (715) 232-1389.

**Rehabilitation Research and Training Center on Enhancing Employability of Individuals with Handicaps, University of Arkansas, 346 West Ave., Fayetteville, AR 72701.** Vernon L. Glenn, Ed.D., Project Director, (501) 575-3656.

**Research and Training Center for Access to Rehabilitation and Economic Opportunity, Howard University, School of Education, 2400**

6th St. N.W., Washington, DC 20059. Sylvia Walker, Ed.D., Project Director, (202) 636-7351.

**Rehabilitation Research and Training Center on Improving Supported Employment Outcomes for Individuals with Developmental and Other Severe Disabilities**, Virginia Commonwealth University, School of Education, MCV Box 568, Richmond, VA 23284. Paul Wehman, Ph.D., Project Director, (804) 257-1851.

**Rehabilitation Research and Training Center for Pediatric Rehabilitation**, University of Connecticut, Department of Pediatrics, 263 Farmington Ave., Farmington, CT 06032. Robert Greenstein, M.D., Project Director, (203) 527-0856.

**Rehabilitation Research and Training Center for Seriously Emotionally Disturbed Children**, University of South Florida, Florida Mental Health Institute, 33301 North 30th St., Tampa, FL 33612. Robert Friedman, M.D., Project Director, (813) 974-4610.

**Transition Institute**, School of Education, University of Illinois at Urbana-Champaign, 110 Education Building, 1310 South Sixth Street, Champaign, IL 61820. Frank Rusch, Ph.D., Project Director, (217) 333-2325.

**The Employment Network**, University of Oregon, 135 Education Building, Eugene, OR 97403. David Mank, Ph.D., Project Director, (503) 686-5311.

**"Financing home care for seriously disabled and chronically ill children,"** Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140. Valerie J. Bradley, Project Director, (617) 876-0426.

**"Research and demonstration project to improve functioning in families with learning disabled children,"** Interamerica Research Association, 1555 Wilson Blvd. #600, Arlington, VA 22209. Delores M. John, Ph.D., Project Director, (703) 522-3332.

**"Community Transition Center,"** Research and Training Center, University of Wisconsin-Stout, Menomonie, WI 54751. Charles C. Coker, Ph.D., Project Director, (715) 232-2603.

**"Transition from school to work for deaf youth,"** University of Arkansas, Fayetteville, AR 72701. Douglas Watson, Ph.D., Project Director, (501) 371-1654.

"The development and evaluation of an intervention program for families with learning disabled youths," University of Kansas, Institute for Research in Learning Disability, 206 Carruth O'Leary Hall, Lawrence, KS 66045. J. Stephen Hazel, Ph.D., Project Director, (913) 864-4780.

### Selected Bibliography

Azornoff, P. (1983). Health, illness and disability: A guide to books for children and young adults. New York: R.R. Bowker.

Batshaw, M. L. (1986). Children with handicaps: A medical primer. Baltimore, MD: P.H. Brookes Pub. Co.

Browder, D. M. (1987). Assessment of individuals with severe handicaps: An applied behavior approach to life skills assessment. Baltimore, MD: P. H. Brookes.

Coker, C., Thomas, D., & Czerlinsky T. (1988). Community transition center model. Menomonie, WI: University of Wisconsin-Stout, Research and Training Center.

Crump, I. M. (1987). Nutrition and feeding of the handicapped child. Boston: Little, Brown.

Esterson, M. M., & Bluth, L. F. (Eds) (1987). Related services for handicapped children. San Diego, CA: College-Hill Press.

Garber, H. L., & McInerney, M. (1987). STORY: A school based program for sequencing the transition of at-risk and retarded youth. Madison, WI: University of Wisconsin Rehabilitation Research and Training Center.

Institute on Rehabilitation Issues (IRI). D. W. Corthell & C. VanBoskirk (Eds.). (1984). Continuum of services: School to work. Menomonie, WI: University of Wisconsin-Stout, Research and Training Center, University of Wisconsin-Stout.

Jones, M. L. (1985). Home care for the chronically ill or disabled child: A manual and sourcebook for parents and professionals. New York: Harper and Row.

Meyer, D. J. (1985). Living with a brother or sister with special needs: A book for sibs. Seattle: University of Washington Press.

Sanders, M. (1983). Clinical assessment of learning problems: Model, process and remedial planning. Cambridge, MA: Brookline Books.

Sarkees, M. D. (1985). Vocational Special Needs. Alsip, IL: American Technical Publishers.

Seligman, M. (1989). Ordinary families, special children: A systems approach to childhood disability. New York: Guilford Press.

Simeonson, R. J. (1986). Psychological and developmental assessment of special children. Boston: Allyn & Bacon.

Taylor, H., Kaygag, M.R., & Leichenko, S. (1989). The ICD Survey III: A report card on special education. New York: Louis Harris and Associates.

Tweedie, D., & Schroyer, E. H. (Eds.) (1982). The multihandicapped hearing impaired: Identification and instruction. Washington, DC: Gallaudet College Press.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations.

Research and Training Centers and demonstration projects with missions related to this area of inquiry.

Universities and colleges with programs concerned with the issues of youth, young adults, and unique differences, and research on disabilities.

State special education divisions and special education departments in urban and regional districts are often a valuable source for information on incidence and needs of youth, particularly their educational and social needs.

# *Chapter 12*

## **Minority, Underserved, and Unserved Populations**

### **Background and Discussion**

There are segments of the disabled population that have never had their unique needs adequately assessed and have traditionally been under-identified and underserved by vocational rehabilitation agencies. These populations include low incidence disabilities (e.g., HIV), low incidence cultures and ethnic groups, and cultural and disability groups that are outside (or overlooked by) the traditional social service systems. For one reason or another such groups are not adequately represented in society's norms and demographics. Thus, their needs have neither been identified nor understood by service providers. American culture purports to value cultural diversity. However, if unique differences of subpopulation groups are not understood or the special population group is unable to communicate their rehabilitation needs the state program will continue to fail to appropriately meet their needs.

While we may be most familiar with how communication is affected by certain disabilities (such as deafness or developmental disabilities), it is also true that communication of needs by some minority groups may also be affected. Cultural and experiential backgrounds of blacks, Native Americans Southeast Asians, South Americans, Hispanics and other groups with experiential differences (e.g., high school drop-outs) may have needs distinct from non-minority individuals. These differences will affect the extent to which traditional approaches to needs assessment are useful and whether needs are being validly identified through those efforts.

How does one then come by this information? How does one find out about experiences and needs that are likely to be unfamiliar? Cultural and language differences must be reasonably accommodated in our assessment methods. The overall survey method may be similar to that used in any well designed survey on disabled persons in general. However, some parts of the process may require greater sensitivity, special accommodation, and, perhaps, greater investment of personal and research resources to obtain a finer understanding of differences.

Another problem in identifying needs that are unique to a special population group is that their needs are masked by the dominance of need among the more prevalent groups with whom the assessment was conducted. For example, the differences in needs and customs among Cambodians, Hmong, and other Southeast Asian refugees are vastly different. Often their unique needs and customs are grouped together among the larger category in rehabilitation codes as "Asian and Pacific Islander."

One of the first steps to take is to accurately identify the target population to be assessed. Some of the major underserved populations that may require special efforts and approaches in order to obtain a valid and useful understanding of their needs are the following populations: Blacks, Cambodians, Hmong, Native Americans, Spanish speaking peoples, homeless and poor, uneducated, high school dropouts, aged, and certain isolationist religious and/or cultural groups. It is important that appropriate target populations be identified and individually surveyed or specifically identified on needs assessment instruments and forms.

Since the customs of different groups can be so different, it is important that advocacy groups, other service organizations, and community leaders serving the target populations be involved in the study process to the greatest extent possible. Personal contact with key informants and agency staff who are familiar with the group and with cultural resource persons is an important step in determining how to effectively identify the needs of these special populations.

These sources can play an important role in locating and defining groups, gaining entrance and acceptance within the community, in designing survey methods to accommodate for group characteristics, and in developing the appropriate interview or survey methods and procedures to gather valid information. It is important to design survey methods and procedures that accommodate for group characteristics (such as the lack of phones), and for language differences that affect the ability to obtain valid information. The design of survey instruments and methods to accommodate group characteristics can be dramatically affected by such differences.

Unique perceptions about oneself, society, service providers, cultural characteristics, and experiences may cause a lack of adequate understanding or responsiveness to "normal" survey techniques. Generalized attitudes regarding the institution sponsoring the study or assumptions about the ethnic background of the researcher conducting the study may also inhibit survey interaction regardless of the personal convictions of the interviewer.

Quality of responses and the participation of underserved persons may also be neutral because of cultural differences. For instance, a disabled Hmong may refuse to express an opinion or give a neutral opinion, not because he/she does not feel strongly, but rather because in that culture such topics may be discussed only by family with clan leaders. Their authority must be consulted before opinions are formulated and more publicly expressed. Mailed surveys may not be returned. In order to address these issues, the use of peers or clan leaders as interviewers to conduct interviews or community meetings may be a more productive means for obtaining needs information.

Hence, family interviews using individuals from within the culture (or staff knowledgeable of the cultural beliefs of the population) may produce more

meaningful results than interviews with individuals. Interpreters or survey staff need to understand the cultural background, as well as know the language of the persons being interviewed, in order to grasp the contextual meanings expressed in a particular assessment situation. In general, before designing a survey, one

must insure that the subjects and researchers share a consistent perception of what is being asked.

### **Special Considerations in Assessing the Needs of These Populations**

The following are important considerations to make when attempting to assess the needs of minority and underserved populations:

1. Make adequate use of community and advisory persons in defining the group, their mores and cultural bases, and for obtaining community cooperation.
2. Make provision for identifying specific subpopulations with which respondents identify.
3. Design data collection methods that accommodate for characteristics and cultural practices that are different from those of the larger population mix.
4. Use advisory bodies consisting of culturally knowledgeable persons to design instrumentation and develop procedures for collecting data.
5. Use persons from the subpopulation to conduct interviews when possible.
6. Review the results with persons knowledgeable of the group to be surveyed, such as community advisory bodies or cultural resource persons, when interpreting the data to insure valid inferences.
7. It may also be necessary to go beyond the normal sources of demographic information since these populations are not adequately represented by census data.
8. Specific information and research resources that should not be overlooked include (a) universities or special public or private agencies that have done or are in the process of conducting studies of the particular group, (b) agency staff who work with the population, (c) churches and religious groups, and (d) advocacy organizations.
9. While advocacy groups represent the needs of individuals and will have an important perspective on those needs, they may or may not have actually conducted research needed to accurately assess the special needs of the

population of concern.

### **Suggested Sources of Information on Needs of These Populations**

#### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of the minority, underserved, and unserved populations. They may be of help for identifying service providers and key informants for the minority, underserved, and unserved populations. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

Association of American Indian Affairs, 95 Madison Ave., New York, NY 10016, (212) 689-8720.

National Advisory Council on Indian Education, 330 C St., SW, Switzer Bldg., Room 4072, Washington, DC 20202-7556, (202) 732-1353.

Clearinghouse on Handicaps, Room 3132, Switzer Bldg., 330 C St., SW, Washington, DC 20202-2524, (202) 732-1241.

Council on Career Development of Minorities, 1341 W. Mockingbird Lane, Suite 412-E, Dallas, TX 75247, (214) 631-3677.

Disability Rights Education and Defence Fund, 2212 Sixth St., Berkeley, CA 94710, (415) 644-2555.

National Association for the Advancement of Colored People (NAACP), 4805 Mt. Hope Dr., Baltimore, MD 21215, (212) 481-4100.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

## Research Centers and Projects

**Rehabilitation Research and Training Center for Native Americans,**  
University of Arizona, 1642 East Helen Street, Tucson, AZ 85719.  
Jennie R. Joe, Ph.D., Project Director, (602) 621-5075.

**Rehabilitation Research and Training Center for Pacific Basin Rehabilitation,** University of Hawaii at Manoa, John A. Burns School of Medicine, 266 North Kuakini Street, Suite 233, Honolulu, HI 96817. Daniel D. Anderson, Ed.D., Director, (808) 537-5986.

**Research and Training Center for Access to Rehabilitation and Economic Opportunity,** Howard University, School of Education, 2400 6th St. NW, Washington, DC 20059. Sylvia Walker, Ed.D., Project Director, (202) 636-7351.

**Rehabilitation Research and Training Center on American Indians,** Northern Arizona University, CU Box 5630, Flagstaff, AZ 86011. Marilyn Johnson, Ph.D., Project Director, (602) 523-6756.

**Rehabilitation Research and Training Center on Improving Rehabilitation Services for Handicapped Persons in the Pacific Basin,** University of Hawaii, School of Medicine, 2444 Dole Street, Honolulu, HI 96822. G. Harley Hartung, Ph.D., Project Director, (808) 949-4588.

**Rehabilitation Research and Training Center on Aging and Developmental disabilities,** University Affiliated Cincinnati for Developmental Disorders, 3300 Elland Avenue, Cincinnati, OH 45229. Jack Rubinstein, M.D., Project Director, (513) 559-4958.

**Rehabilitation Research and Training Center on Aging.** Professional Staff Association, Rancho Los Amigos Medical Center, Inc., 7600 Consuelo Street, Downey, CA 90242. Bryan J. Kemp, Ph.D., Project Director, (213) 940-7402.

**Rehabilitation Research and Training Center for Rehabilitation of Elderly Disabled Individuals,** University of Pennsylvania Hospital, 3400 Spruce Street, Box 590, Philadelphia, PA 19104. Stanley J. Brody, J.D., M.S.W., Project Director, (215) 662-3700.

## Selected Bibliography

Institute on Rehabilitation Issues. (In press). Aging in America: Implications for vocational rehabilitation and independent living. Menomonie: University of Wisconsin-Stout, Research and Training Center.

Institute on Rehabilitation Issues. (1989). Vocational rehabilitation services to persons with H.I.V. (AIDS). Menomonie: University of Wisconsin-Stout, Research and Training Center.

Institute on Rehabilitation Issues. (1981). Delivery of rehabilitation services to inner city nonwhites. Menomonie: University of Wisconsin-Stout, Research and Training Center.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations.

Research and Training Centers with missions related to the special needs of minorities.

Universities and colleges with programs concerned with the issues of underserved populations, minorities, culturally unique differences, and research on disabilities.

# *Chapter 13*

## **Native Americans**

### **Background and Discussion**

The State Plan for vocational rehabilitation services requires state vocational rehabilitation agencies to provide services to Native Americans who are handicapped and who reside in the state to the same extent that these services are provided to other significant groups of persons with handicaps in the state. In order for state agency administrators to develop and implement programs and policies to fulfill these requirements and the requirements of 34 CFR 361.17, they will need information and data related to the following issues and questions:

1. What is the population and rehabilitation needs of individuals with handicaps in the state?
2. What is the population of Native Americans with handicaps in the state?
3. What are the needs for vocational rehabilitation services among the state's population of Native Americans with handicaps?
4. What are the results of the state agency's review of a broad variety of means and methods to provide, expand, and improve services to Native Americans with handicaps in order to determine which services are most effective?
5. What are the results of the agency's review of the appropriateness of its criteria for use in determining Native Americans to be ineligible for vocational rehabilitation?
6. Where are Native Americans located in rural and reservation areas and within urban settings?

Native Americans with disabilities, as a group, are not identified to the extent that they should be in rehabilitation needs assessment studies. More often than not, reference to them and their needs occurs in the description of the general population of individuals with disabilities. Consequently, large numbers of Native Americans who live in urban settings or who live on federal or state reservations (a) are often not systematically included in the rehabilitation needs assessment studies or (b) find the cultural basis for their unique needs are not examined if they are represented. Special efforts and methods are needed in order to assure that Native Americans both on and off reservations are identified and their rehabilitation services needs are noted in statewide needs assessment studies and reports.

Sources of useful information and data on the needs of Native Americans are becoming less difficult to find. The U.S. census reports and state and

national health services reports now contain some information on Native Americans. The U.S. Bureau of Indian Affairs and the National Advisory Council on Indian Education are among the more knowledgeable sources of general demographic information on Native Americans living on reservations. However, evaluators and researchers will need to seek firsthand information from state Indian tribal councils and from social service agencies and health agencies that relate exclusively to or who purposely extend services to Native Americans.

In collecting information and data to assess the rehabilitation service needs of Native Americans, researchers and program evaluators must be careful to not violate cultural mores and to adhere to tribal protocol. For example, Native Americans' elders and tribal chiefs command very high levels of respect and authority. Access to the tribe is likely to be in their hands. It may be advisable to consult with these persons before conducting surveys or interviews in American Indian communities. Further, there may be other cultural or language barriers that must be addressed if the researcher is to obtain useful information from individuals surveyed or interviewed.

### **Special Considerations in Assessing the Needs of Native Americans with Disabilities**

Some specific recommendations for carrying out research on Native American needs include the following:

1. Make adequate use of tribal and advisory persons in defining the group, their mores, cultural bases, and for obtaining tribal or individual cooperation.
2. Make provision for identifying the specific tribes with which respondents identify.
3. Design data collection methods that accommodate the characteristics and cultural practices that are different from those of the larger population mix.
4. Use advisory bodies consisting of persons knowledgeable of the cultural and tribal differences when designing instrumentation and developing procedures for collecting data.
5. Use Native Americans familiar with tribal customs to conduct interviews when possible.
6. Review the results with Native American leaders and persons knowledgeable of the tribal customs and values, such as a tribal councils or cultural resource persons, when interpreting the data to insure valid inferences.

### **Suggested Sources of Information on Needs of Native Americans with Disabilities**

#### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of Native Americans. They may be of help for identifying service providers and key informants for Native Americans. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

**Association of American Indian Affairs, 95 Madison Ave., New York, NY 10016, (212) 689-8720.**

**National Advisory Council on Indian Education, 330 C St., SW, Switzer Bldg., Room 4072, Washington, DC 20202-7556, (202) 732-1353.**

**National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.**

**National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.**

**Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.**

#### **Research Centers and Projects**

**Rehabilitation Research and Training Center on American Indians, Northern Arizona University, CU Box 5630, Flagstaff, AZ 86011. Marilyn Johnson, Ph.D., Project Director, (602) 523-6756.**

**Rehabilitation Research and Training Center on Native Americans, University of Arizona, 1642 East Helen Street, Tucson, AZ 85719. Jennie Joe, Ph.D., Project Director, (602) 621-5075.**

#### **Selected Bibliography**

**Borunda, P., & Shore, J. H. (1978). Neglected minority: Urban Indians and mental health. *International Journal of Social Psychiatry*, 24, 220-224.**

EchoHawk, M. (1980). Issues related to delivery of services to American Indian children. In Manpower Considerations in Providing Mental Health Services to Ethnic Minority Groups, Mental Health Manpower Planning and Development Project of the Western Interstate Commission for Higher Education, Boulder, CO, 73-79.

Institute for Information Studies. (1985). Cross-cultural rehabilitation: Working with the Native American population. Rehab Brief, IX(5).

Kline, B. (1987). Reference encyclopedia of the American Indian: Fourth edition-Two volumes in one. New York: Todd Publication.

Morgan, C. O., Guy, E., Lee, B., and Cellini, H. R. (1986). Rehabilitation services for American Indians: The Navajo experience. Journal of Rehabilitation, 52(2), 25-31.

Morgan, J., & O'Connell, J. C. (1985). Disabilities among adult Native Americans: An analysis of Rehabilitation Services Administration data. Paper presented at the Annual Conference of the National Association of Rehabilitation Research and Training Centers in May 1985 in Washington, DC.

- Native American Research and Training Center (1988). A survey of vocational rehabilitation counselors who work with American Indians. Journal of Applied Rehabilitation Counseling, 19(4), pp. 29-34.

O'Connell, J. C. (1986). Native American rehabilitation: A bibliographic series. Flagstaff, AZ: Northern Arizona Native American Research and Training Center.

O'Connell, J. C. (1987). A study of the special problems and needs of American Indians with handicaps both on and off the reservation, Vols. I-III. Flagstaff, AZ: Northern Arizona Native American Research and Training Center.

Powless, D. (1986). Vocational rehabilitation of American Indians in Wisconsin. Paper presented at Native American National Research Symposium, Northern Arizona University and University of Arizona, Scottsdale, AZ.

Shore, J. H., & Von Fumetti, B. (1972). Three alcohol programs for American Indians. American Journal of Psychiatry, 128, 134-138.

**Standard Resources for Assistance**

Tribal councils, elders, and chiefs within each specific tribe. It is most likely that needs and ways to address needs will be quite distinct for different Indian nations within the state.

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of Indian rights, particularly in urban areas.

The U.S. Bureau of Indian Affairs, the National Advisory Council on Indian Education, and related government units within the state education, health, labor and economic development, and tourism agencies.

The two Research and Training Centers with missions related to this area of inquiry (listed above).

Universities and colleges with programs concerned with Native American programs and other programs that teach and conduct research on the unique cultural differences and disabilities of minority populations.

# *Chapter 14*

## **Women With Disabilities**

### **Background and Discussion**

The State-Federal Vocational Rehabilitation Program was established to provide vocational rehabilitation services to all persons with handicaps that interfere with their employability. Vocational rehabilitation agency State Plans require state agencies to conduct statewide studies to determine the relative needs for vocational rehabilitation services of different segments of the state's population of individuals with handicaps. These statewide studies are to include a review of a broad variety of methods and procedures to provide, expand, and improve vocational rehabilitation services in order to determine which means and methods are most effective.

Discrimination based on gender, ethnicity or disability is prohibited by Title VII of the 1964 Civil Rights Act, and Title IX of the Educational Amendments of 1972. Title V of the Rehabilitation Act of 1973, as amended, also prohibits discrimination in the provision of services to and in the employment of persons with disabilities. Although women with disabilities are included in needs assessment studies, the concern is that rehabilitation program evaluators and managers in their assessment of needs often do not design the studies to consider the special needs of women.

For example, women with disabilities are often single heads of households and may need or be receiving some form of financial assistance. They may often have children and require child care support if they are to be involved in a rehabilitation program. A recent study showed that women in the age groups 16-24 and 45-54 are not being served in proportion to their number in the population by the rehabilitation services delivery system (Region V Study Group, 1987).

### **Special Considerations in Assessing the Needs of Women with Disabilities**

1. Needs assessment methods should be designed to consider the non-traditional vocational rehabilitation needs of women in ways that do not exclude them from consideration for any occupation.
2. Needs assessment methods should be designed to identify the primary care-giver needs of persons with disabilities regardless of their gender.

## **Suggested Sources of Information on Needs of Women with Disabilities**

### **Associations and Organizations That Are Resources**

The following organizations can provide assistance in assessing the rehabilitation service needs of women with disabilities. They may be of help for identifying service providers and key informants for women with disabilities. They also usually can provide some prevalence, incidence, social indicator, and demographic data of varying quality for this group.

**Clearinghouse on Handicaps, Room 3132, Switzer Bldg., 330 C St., SW, Washington, DC 20202-2524, (202) 732-1241.**

**Disability Rights Education and Defence Fund, 2212 Sixth St., Berkeley, CA 94710, (415) 644-2555.**

**National Association of the Deaf, 814 Thayer Ave., Silver Spring, MD 20910, (301) 587-1788.**

**National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.**

**National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.**

**National Womens Health Network, 1325 G St., NW, Lower Level, Washington, DC 20005, (202) 347-1140.**

**Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.**

### **Research Centers and Projects**

**Rehabilitation Research and Training Center for Access to Rehabilitation and Economic Opportunity, Howard University, School of Education, 2400 6th St. NW, Washington, DC, 20059. Sylvia Walker, Ed.D., Program Director, (202) 636-7351.**

**Rehabilitation Research and Training Center on Community Integration Resource Support, Syracuse University Center on Human Policy, 4E**

Huntington Hall, Syracuse, NY 13210. Steven Taylor, Ph.D., Project Director, (315) 423-3851.

Rehabilitation Research and Training Center in Independent Living, P.O. Box 20095, Houston, TX 77030. Marcus Fuhrer, Ph.D, Project Director, (713) 799-7011.

Rehabilitation Research and Training Center in Independent Living, 510 16th St., Suite 100, Oakland, CA 94612. Ed Roberts, Director, (415) 763-4100.

Rehabilitation Research Training Center on Rural Rehabilitation Services, University of Montana, Missoula, MT 59812. Richard Offner, Ph.D., Project Director, (406) 243-5467.

Rehabilitation Research and Training Center on Aging and Developmental Disabilities, University Affiliated Cincinnati for Developmental Disorders, 3300 Elland Avenue, Cincinnati, OH 45229. Jack Rubinstein, MD, Project Director, (513) 559-4958.

Rehabilitation Research and Training Center on Aging, Professional Staff Association, Rancho Los Amigos Medical Center, Inc., 7600 Consuelo Street, Downey, CA 90242. Bryan J. Kemp, Ph.D., Project Director, (213) 940-7402.

Rehabilitation Research and Training Center for Rehabilitation of Elderly Disabled Individuals, University of Pennsylvania Hospital, 3400 Spruce Street, Box 590, Philadelphia, PA 19104. Stanley J. Brody, JD, MSW, Project Director, (215) 662-3700.

Institute for Health and Aging, University of California, Room N631, San Francisco, CA 94143, (415) 476-2977.

### **Selected Bibliography**

American Council on Life Insurance. (1983). Fact sheet on women: Women and work. Hartford, CT: Author.

Bowe, F. (1984). Disabled women in America. Washington, DC: The Presidents Committee on Employment of the Handicapped.

Brooks, N., & Deegan, M. (1981). Women and disability, the double handicap. Journal of Sociology and Social Welfare, 8(1), 129-133.

Carrick, M. M., & Bibb, T. (1982). Disabled Women and Access to Benefits and Services. In L. Perlman & K. Arneson (Eds.). Women and

rehabilitation of disabled persons: A report of the sixth Mary E. Switzer Memorial Seminar (pp. 28-37). Alexandria, VA: National Rehabilitation Association.

Danek, M. M., & Lawrence, R. E. (1985). Women in rehabilitation: An analysis of state agency services to disabled women. Journal of Applied Rehabilitation Counseling, 16(1), 16-18.

Deegan, M. (1981). Multiple minority groups: A case study of physically disabled women. Journal of Sociology and Social Welfare, 8, 129-133.

Reder, N., Arrindell, D., & Middleton, M. (1984). Meeting the employment needs of women: A path out of poverty? (Publication No. 359) Washington, DC: League of Women Voters Fund.

Region V Study Group. (1987). Region V study of access, services and benefits from vocational rehabilitation 1972 to 1984: A gender perspective. Menomonie, WI: University of Wisconsin-Stout, Research and Training Center. This document contains an extensive bibliography on rehabilitation and women's needs as well as comparable entry and closure data.

Tate, D., & Weston, N. (1982). Women and disability: An international perspective. Rehabilitation Literature, 43, 117-118.

Vash, C. (1982). Employment issues for women with disabilities. Rehabilitation Literature, 43, 198-207.

### Standard Resources for Assistance

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of women with disabilities.

Research and Training Centers with missions on independent living, rural rehabilitation, aging, and economic opportunity.

Universities and colleges with non-traditional student programs, domestic abuse programs, women's studies programs, marriage and family counseling programs, and rehabilitation and other programs that teach and conduct research on the unique differences brought about by disability for women.

# *Chapter 15*

## **Rehabilitation Facilities**

### **Background and Discussion**

Any meaningful attempt to align service delivery capacity with priority unmet needs identified through a needs assessment must include a careful consideration of rehabilitation facility services. Typically, a state agency spends between 20 and 35 percent of its case service funds for facility services. As early as the late 1970s, state agencies developed statewide plans to monitor and direct the provision of crucial facility services in response to State Plan requirements. A decade later, newly expanded State Plan needs assessment requirements continued to reflect the central role facility services play in the vocational rehabilitation process.

The legal requirements for state agencies to include facility services in the needs assessment process reside in two sections of the regulations for the 1988 Amendments of the Rehabilitation Act (P.L. 99-506):

[The] State Plan must assure that the designated State unit maintains a State Rehabilitation Facility Plan which includes an inventory of rehabilitation facilities and rehabilitation facilities' services available within the State and a description of the utilization patterns of the facilities and their utilization potential. The State must assure that the designated State unit utilizes existing rehabilitation facilities to the maximum extent feasible to provide vocational rehabilitation services to handicapped individuals.... (Section 34 CFR 361.22 )

The State Plan must assure that the state unit conducts continuing Statewide studies of the needs of individuals with handicaps within the State, including a full needs assessment for serving individuals with severe handicaps; the State's need for rehabilitation facilities; and the methods by which these needs may be most effectively met. (Section 34 CFR 361.17(a))

Together these sections require the state agency to perform the following actions in order to prepare a State Rehabilitation Facility Plan:

1. Inventory facilities within the state and the types of services that they provide.
2. Identify the present level of utilization of each type of service offered within each facility in the state.
3. Determine the state's need for new, expanded, and modified facility service capacity by service type.

4. Develop a prioritized list of facility projects necessary to achieve the state agency's short-range goals for facility service capacity adjustments.
5. Develop and maintain a state facility services plan (with the active participation of a representative group of service providers and consumers) that contains the information described in points one through four above.

### **Methods for Obtaining Data**

Vocational rehabilitation agencies have developed a variety of methods to assess the need for rehabilitation facility services on an ongoing basis. The usual techniques include service inventories, utilization analyses and projections, project priority lists, and some mechanism for service provider input. Possible methods and tools for fulfilling the five statutory requirements for Facility Plan development are discussed below.

#### **Current Utilization**

The most accurate sources of current facility service utilization information are reports produced by the state agency from monthly facility reports (see Figure 2. Rehabilitation Facility Monthly Report). In addition to average daily enrollments and average daily attendance for frequently used services, this report will list clients beginning service during the month by service type and will also list placements into competitive and sheltered employment during the month. These monthly report data can be aggregated into fiscal year reports, and fiscal year facility reports also can be aggregated across facilities that serve the same county, administrative area, or administrative region to yield a more global picture of current utilization and movement of clients.

#### **Inventory of Facilities and Services**

Price lists, facility contracts, fee schedules are sources of inventory data. These sources specify the types of services available, service unit size, and cost per unit. Figure 3 provides an example of the content for a typical facility fee schedule. In some states, rehabilitation facilities are asked to provide complete price lists of their services, and these can be useful in building a comprehensive picture of rehabilitation services available within the state. As a part of a legal agreement, the accuracy of the cost list is usually high and minimal expense is involved for manipulating these data for needs assessment purposes.

FACILITY MONTHLY REPORT							
Facility		Reporting Dates		to			
Address		Phone		Contract Number			
		Contact Person		Account			
				Dollars Charged	\$		
Contracted Services	Service Code	Total Fee Charged	Total Days or Service Units	New Starts	Clients Completed	Average Daily Attendance	
<b>Evaluation and Assessment</b>							
Vocational	24						
Psychological	25						
Hearing	29						
<b>Vocational Training and Employment</b>							
Vocational Training	75						
Work Adjustment	81						
Placement Services	90						
Supported Employment	98						
Extended Employment	93						
<b>Other Services</b>							
Transportation	102						
Residential	110						
<b>TOTALS FOR MONTH</b>							
(Attach list of clients starting and completing each service and service outcomes.)							

**Figure 2. Rehabilitation Facility Monthly Report**

FACILITY FEE SCHEDULE							
Facility		Effective Dates		to			
Address		Phone		Contract Number			
		Contact Person		Account			
				Total Dollars			
Contracted Services	Service Code	Fee Schedule (\$ Rate)	Basic or Unit Base	Restrictions and Limitations			
<b>Evaluation and Assessment</b>							
Vocational	24		4 Days	Maximum of 10 days per client			
Psychological	25		6 Hours				
Hearing	29		3 Hours	Maximum of 3 testings			
<b>Vocational Training and Employment</b>							
Vocational Training	75		Slot				
Work Adjustment	81		6 Hour Day	Prior approval required			
Placement Services	90		60 + days				
Supported Employment	98		1 Hour	Job coaching			
Extended Employment	93		Slot				
<b>Other Services</b>							
Transportation	102		Mile				
Residential	110		Month	Related medical not covered			

**Figure 3. Fee Schedule**

Another source of inventory information is the facility inventory survey, an example of which is found in Figure 4 is an example of a Facility Service Inventory. In addition to listing each type of services available at the facility, capacity is expressed in average daily enrollments of vocational rehabilitation clients for the most frequently utilized services. Average daily enrollments recorded during the most recent fiscal year for vocational rehabilitation clients is computed by summing actual daily enrollments and dividing by the number of work days in the month.

### Projected Utilization

As discussed in Volume I, priority unmet needs for facility and other services can be estimated by any one or a combinations of a variety of techniques. Techniques typically used include direct service provider surveys, key informant surveys, community forums and hearings, case studies, social indicators, and prevalence-incidence surveys.

A common source of data used to identify areas which rehabilitation facility service capacity might be increased is the client waiting list. In some states, a client in a hold status can be temporarily transferred to an area-wide waiting list caseload. In other states, referrals awaiting facility services are simply listed by the local vocational rehabilitation office and are receive facility services in order of their initial referral date. In some cases facilities maintain waiting lists. Where substantial waiting lists continue month after month, more detailed data should be sought to determine whether this actually represents a need to expand facility service capacity. One common problem with waiting lists, though, is that they are subject to manipulation by both facility and vocational rehabilitation personnel.

### Prioritized Facility Projects List

Once projected utilization and current capacity are established, they can be aggregated for each service type and administrative area. Needed additional capacity (if any) for each service type can be found by subtracting current capacity from projected utilization. New federally mandated target groups (e.g., persons with traumatic brain injuries) may require additional service capacity. These needs may be given receive top ranking among planned facility projects. Next in priority order may be projects which address needs of disability groups which the state's needs assessment data show are underserved.

The resulting prioritized list of projects constitutes a key component of the State Rehabilitation Facility Plan. This list could be addressed through the Facility Establishment, Facility Construction, or Services to Groups Grant Programs if funds are available (or can be allocated to) for these purposes. Otherwise, these projects could be addressed by new or expanded facility services.

## VOCATIONAL REHABILITATION FACILITY SERVICE INVENTORY

Facility	POS Code	Date	Administrative Area
Available Services	Service Offered (Check)	Current Service Utilization (Average Daily Enrollment) Only VR Referrals	Potential Service Utilization (Estimated Openings for FY 1991) VR All Referral Sources Referrals
<b>Evaluation and Assessment</b>			
Vocational			
Medical			
Psychiatric			
Psychological			
Social			
Speech			
Hearing			
<b>Unduplicated Totals</b>			
<b>Restoration and Training</b>			
Medical Supervision			
Physical Therapy			
Occupational Therapy			
Prosthetic Fitting			
Orthotics Fitting			
Psychiatric Therapy			
Psycho-social Counseling			
Speech Therapy			
Audiology			
Social Case Work/Managmt			
<b>Unduplicated Totals</b>			
<b>Vocational Training and Employment</b>			
Vocational Counseling			
Vocational Training			
Work Activities			
Work Adjustment			
Placement Services			
Supported Employment			
Extended Employment			
<b>Unduplicated Totals</b>			
<b>Personal Care Training</b>			
Independent Living			
Educational Services			
Personal Adjustment			
Orientation and Mobility			
Activities Daily Living			
<b>Unduplicated Totals</b>			
<b>Other Services</b>			
Maintenance			
Transportation			
Residential			
Recreation			
<b>Unduplicated Totals</b>			
<b>Unduplicated Totals Across Services</b>			

Figure 4. Facility Service Inventory

## Consumer and Service Provider Involvement

Like the State Plan, the state agency must afford citizens the opportunity to voice their reactions to the State Rehabilitation Facility Plan via public hearings. Other ways of securing consumer and provider input include surveys of former clients, other consumers, vocational rehabilitation counselors, independent living center personnel, facility staff, advocacy groups, legislators, and reviews of client appeals.

The key questions to ask are the following: (a) What group or groups of individuals with disabilities who should have access to vocational rehabilitation do not have access? (b) What services should be provided which are not currently available? (c) How can multiple funding sources be effectively coordinated? Advisory committees composed of consumers and service providers can provide guidance in gathering and analyzing facility needs assessment information as well as publicizing the contents of the finished State Rehabilitation Facility Plan.

### Using the Data

Gathering and analyzing facility needs assessment data is a very time consuming process. Securing a consensus among consumers and professionals who have strong commitments to a wide variety of viewpoints is difficult. Yet, once agreement is attained, the Rehabilitation Facility Plan and the data which support it have a variety of important applications. The most important of these uses are discussed below.

### Budget Requests

The Rehabilitation Facility Plan estimates the size and characteristics of the caseload to be developed in the future as well as the type, quantity, cost, and location of the facility services these clients will need. This is precisely the type of information that should be found in a budget justification. Moreover, the methodology used to estimate the need for facility services can be used to generate estimates for needed services secured from other vendors as well.

If a variety of consumers and service providers helped shape the Rehabilitation Facility Plan, their understanding of it will more likely lead to their active support of a budget request than if they do not understand the request because they had not been involved in the Plan development. In addition, broad understanding and support of the Facility Plan can stimulate local collaborations and involve multiple funding sources that otherwise would not occur.

## Facility Grants

The Rehabilitation Facility Plan both provides the focus and helps to establish priorities among service needs that the state agency chooses to address through Facility Grant Programs. The types, amounts, and locations of service capacity to be added are identified in the Rehabilitation Facility Plan. Measurable outcomes can be added to grant specifications to insure that the recipient's performance can be satisfactorily tracked and evaluated over the life of the grant.

For example, suppose that seven new job seeking skills slots are needed in one county and that the average length of time for job seeking skills training is four weeks. A grant recipient would be expected to turn over a class of seven clients every four weeks and serve as many as 91 (i.e.,  $7 \times 13$ ) additional clients per year. As the agency is also interested in the quality of the training, one of several possible measurable objectives this grant might be have to address could be as follows: To increase the annual number of competitive placements commensurate with the clients's vocational goal by at least 40 the first grant year and 70 the second grant year, and for each year thereafter, over the present level.

## Request for Proposal Process

Like facility grants, the Rehabilitation Facility Plan provides the focus and priorities for expenditure of specially earmarked funds for facility services via the request for proposal process. Again Facility Plan specifications for needed services would be augmented with measurable, outcome-oriented objectives so that recipient performance can be tracked and evaluated.

## Purchase of Service Agreements

The Rehabilitation Facility Plan provides guidelines for reviewing and modifying existing agreements, as well as creating new agreements. As a part of these negotiations, service capacities can be increased, decreased or eliminated as called for by the Rehabilitation Facility Plan. These adjustments allow facilities to reallocate or remove unused resources where agreed upon outcomes or activities are not being performed.

## Planning and Budgeting

Desired changes in current caseloads identified in the Plan provide the basis for establishing case service goals for counselors, for administrative areas, and for geographic regions. Methods used to estimate anticipated facility service costs can also be used to estimate case service costs as a whole. These cost estimates can provide the basis for making budget allocations among counselors, administrative areas, and regions. Some desired caseload shifts may require

additional staff or reassignment of existing staff.

### **Public Relations**

Implementation of the facility projects list contained in the Facility Plan affords the opportunity to focus media attention on new capacity to serve vocational rehabilitation clientele as they are implemented. This exposure can cultivate a more positive image for both the state agency and the local facility as well as help recruit referrals.

### **Evaluation**

The State Rehabilitation Facility Plan should be a bench mark against which progress toward desired size, composition and distribution of the statewide facility caseload is annually evaluated. The results of this comparison should be discussed with field staff and appropriate adjustments made as needed in targeted caseloads and counselor case service goals. Progress toward these goals for each facility project listed in the Facility Plan should be reviewed annually in light of any adjustments made in either the targeted caseloads or counselor goals. These modifications should be discussed with the responsible facility staff and project goal revised accordingly.

Needs assessment for facility services is an ongoing, annual event. The tools discussed and displayed here are examples only. Each state vocational rehabilitation program has developed its own tools for measuring facility utilization and outcomes. These are incorporated in planning for needed future capacity. When these activities are combined with general needs assessment techniques (e.g., key informant surveys), needs for facility services are better defined.

### **Suggested Sources of Information on Need for Facility Services**

#### **Associations and Organizations Which are Resources**

Administration on Developmental Disabilities, U.S. Department of Health and Human Services, 3rd and Independence Avenues, Washington, DC 20201, (202) 245-2390.

Commission on Accreditation of Rehabilitation Facilities (CARF), 101 N. Wilmot Road, Suite 500, Tucson, AZ 85711, (602) 748-1212.

Goodwill Industries of America, Inc. (GIA), 9200 Wisconsin Ave., Bethesda, MD 20814, (301) 530-6500.

International Association of Psychosocial Rehabilitation Services (IASPRS), 5550 Sterrett Place, #214, Columbia, MD 21044, (301) 730-7190.

Materials Development Center, Stout Vocational Rehabilitation Institute, University of Wisconsin-Stout, Menomonie, WI 54751, (715) 232-1342.

National Association of Jewish Vocational Services (JVS), 101 Gary Court, Staten Island, NW 10314, (718) 370-0437.

National Association of Protection and Advocacy Systems, 900 Second Street, NE, Suite 211, Washington, DC 20002, (202) 408-9514.

National Association of Rehabilitation Facilities (NARF), P.O. Box 17675, Washington, DC 20041, (703) 648-9300.

National Clearing House of Rehabilitation Training Materials (NCHRTM), Oklahoma State University, 115 Old USDA Bldg., Stillwater, OK 74078, (405) 624-7650.

National Easter Seal Society (NESS), 1350 New York Avenue, NS, Suite 415, Washington, DC 20005, (202) 347-3066.

National Industries for the Blind (NIB), 524 Hamburg Turnpike, Wayne, NJ 07470, (201) 595-9200.

National Industries for the Severely Handicapped (NISH), 2235 Cedar Lane, Vienna, VA 22180, (703) 560-6800.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, D.C. 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

State chapters and associations of vocational, medical, and psychosocial rehabilitation centers.

Vocational rehabilitation facility specialists, rehabilitation counselors, and specialists in own and other state agencies.

State mental health, developmental disabilities, and special education agencies or divisions may have valuable data on service utilization and population needs.

### **Research Centers and Projects**

**Rehabilitation Research and Training Center on New Directions for Rehabilitation Facilities**, University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, School of Education and Human Services, Menomonie, Wisconsin 54751, Daniel C. McAlees, Ph.D., Project Director, (715) 232-1389.

**Rehabilitation Research and Training Center on Enhancing Employability of Individuals With Handicaps**, University of Arkansas, 346 North West Avenue, Fayetteville, AR 72701, Vernon L. Glenn, Ed.D., Project Director, (501) 575-3656.

**Rehabilitation Research and Training Center on Rural Rehabilitation Services**, University of Montana, 33 Corbin Hall, Missoula, MT 59812, Richard B. Offner, Ph.D., Project Director, (406) 243-5467.

**Rehabilitation Research and Training Center in Improving the Management of Rehabilitation Information Systems**, West Virginia University, WV Division of Rehabilitation Services, One Dunbar Plaza, Suite E, Dunbar, WV 250640, Joseph B. Moriarty, Ph.D., Project Director, (304) 766-7138.

**Rehabilitation Engineering Center on Modifications to Worksites and Educational Settings**, Cerebral Palsy Research Foundation of Kansas, Inc., 2021 North Old Manor, Box 8217, Wichita, KS 67308, John H. Leslie, Ph.D., Project Director, (316) 688-1888.

**Rehabilitation Engineering Center on the Quantification of Human Performance**, Massachusetts Institute of Technology, Harvard-MIT Rehabilitation Engineering Center, 77 Massachusetts Avenue, Cambridge, MA 02139, Robert W. Mann, Sc.D., Project Director, (617) 253-0460.

**Rehabilitation Engineering Center on the Quantification of Human Performance**, Ohio State University, Research Foundation, 1314 Kinear Road, Columbus, OH 43212, Sheldon R. Simon, M.D., Project Director, (614) 293-8710.

Rehabilitation Engineering Center for the Delivery of Cost Effective Rehabilitation Engineering Services, South Carolina Vocational Rehabilitation Department, Office of the Commissioner, P.O., Box 15, West Columbia, SC 29171, Anthony Langton, Project Director, (803) 734-5301.

Rehabilitation Engineering Center on Access to Computers and Electronic Equipment, University of Wisconsin-Madison, Trace Center, 750 University Avenue, Madison, WI 53706, Gregg Vanderheiden, Ph.D. Project Director, (608) 262-3822.

### **Selected Bibliography**

Auvenshine, C. D., & Mason, E. J. (1982). Needs assessment in planning rehabilitation services, Journal of Rehabilitation Administration, 6(2), 56-62.

Babbie, E. R. (1973). Survey research methods. Belmont, CA: Wadsworth Publishing Co.

Bennett, E. C. (1975). Estimating need and demand for vocational rehabilitation services. In I. P. Robinault (Ed.), Program planning and evaluation, selected topics for vocational rehabilitation. (pp. 7-17). New York: ICD Rehabilitation and Research Center, Research Utilization Laboratory.

Collington, F. (1984). Estimating need for rehabilitation services for use in program resource allocation in the State of Maryland. Berkeley, CA: VP Techs Monograph Series #22.

Commission on Accreditation of Rehabilitation Facilities (CARF). (1990). Standards manual for organizations serving people with disabilities. Tucson: Author.

Greenleigh Associates, Inc. (1975). The role of the sheltered workshop in the rehabilitation of the severely handicapped. Report to the Department of Health, Education and Welfare, Rehabilitation Services Administration.

Haber, L. D. (1987). State disability prevalence rates: An ecological analysis of social and economic influences on disability, National Institute on Disability and Rehabilitation Research, Washington, D.C.

Menz, F. E. (1986). Community-based vocational rehabilitation facility manpower need revisited: 1980 and 1984 survey findings compared. Menomonie: University of Wisconsin Stout, Research and Training Center.

Menz, F. E. (1988). 1987 survey of rehabilitation facilities: Summary and projections. Menomonie, WI: Rehabilitation Research and Training Center, University of Wisconsin-Stout.

Miller, J. V., & Wargel, J. F. (1979). Developing state agency facility plan: A guide to planning and implementation. Ann Arbor, MI.: The University of Michigan Rehabilitation Research Institute, School of Education.

National Easter Seal Society (1984). Conducting needs assessment: A program portfolio resource manual. Washington, DC: Author.

Neuber, K. A. (1980). Needs assessment: A model for community planning. Sage Human Services Guides, Vol. 14. Newbury Park, CA: Sage Publications.

Ohio Department of Mental Health (1983). The mental health needs assessment puzzle: Guide to a planful approach. Columbus, OH: Author.

Rehabilitation Services Administration. (1985). Model state agency plan for rehabilitation facilities. RSA-PI-85-02. Author.

Struthers, R. D. (1976). Considerations in using global need estimates for planning rehabilitation services. American Journal of Rehabilitation, 42(1), 3-6.

Struthers, R. D. (1986). Methods to obtain and use information about the number of people needing rehabilitation services and the services needed. Lansing, MI: Michigan Rehabilitation Services Division.

### Standard Resources for Assistance

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with disabilities.

The Research and Training Centers and Rehabilitation Engineering Centers with a mission in this area.

Universities and colleges with programs concerned with training of rehabilitation and rehabilitation facility personnel. Particularly to be considered are those college and university programs which teach and conduct research on the use and delivery of rehabilitation services to severely disabled persons.

State mental health, developmental disabilities, and special education agencies or divisions may have valuable data on service utilization and

population needs and may be a cooperating resource with which to coordinate the assessment efforts.

# *Chapter 16*

## **Supported Employment**

### **Background and Discussion**

The Rehabilitation Act of 1973, as amended in 1986, includes Title VI, Part C Supported Employment Services for Individuals with Severe Handicaps. The intent and target populations for supported employment are defined in Section 7(18) of the Rehabilitation Act:

The term 'supported employment' means competitive work in integrated work settings (a) for individuals with severe handicaps for whom competitive employment has not traditionally occurred, or (b) for individuals for whom competitive employment has been interrupted or intermittent as a result of a severe disability, and who because of their handicap, need ongoing support services to perform such work. Such term includes transitional employment for individuals with chronic mental illness. For the purposes of this Act, supported employment as defined in this paragraph may be considered an acceptable outcome for employability.

Section 634 (b) 2 of the Act requires each state to submit a three-year Supported Employment State Plan Supplement which addresses the following:

Specify the results of the needs assessment conducted under Title I of this Act of individuals with severe handicaps as such assessment identifies the need for supported employment services, including the coordination and use of information within the State relating to section 618(b)(3) of the Education of the Handicapped Act.

Describe the quality, scope and extent of supported employment services to be provided to individuals with severe handicaps under this part, and specify the State's goals and plans with respect to the distribution of funds received under section 635.

Furthermore, Sections 101(a)(23)(A) and (B) of the Act require agencies to conduct public meetings throughout the state to allow interested groups, organizations, and individuals the opportunity to comment on the State Plan and Title VI, Part C Supplement and document this input as well as the state's response along with the State Plan.

Under the Education of the Handicapped Act, state education agencies are required to report annually to state vocational rehabilitation agencies the number of individuals involved in special educational services. The reference requiring the use of special education data implies that these students comprise a major component of the supported employment target population.

## **Issues and Considerations in Assessing Need for Supported Employment**

Supported employment is still a developing rehabilitation modality intended to meet the unique needs of individuals with severe impairments. The basic parameters of the supported employment option are still being defined. Many of the special considerations for supported employment needs assessment are more issue-oriented than they are method-oriented. The unresolved issues that will affect how needs assessment is designed and conducted are philosophical, population related, service definition, and interagency issues.

### **Philosophical Issues**

There are two philosophical issues that impact on supported employment needs assessment. The first is that the concept of employment readiness is not considered relevant in this program. Individuals, by definition, are not job ready if they are in need of supported employment. Therefore, no training to prepare for employment is required. This means that any training required occurs after a job is located. To some extent, this is a reversal of the traditional rehabilitation case service process. Thus, the needs assessment must focus much more on what would be considered post-employment services.

The second philosophical issue is integration of individuals through supported employment. This implies that individuals in sheltered employment, work activities, or day service programs are not at regular sites of employment where they can interact with nondisabled individuals and should be moved into supported employment. While vocational rehabilitation agencies are required to assess the need for rehabilitation facilities, the development of more supported employment services could reduce the need for facilities to provide sheltered or protected environments. Many rehabilitation facilities are involved in a process to convert parts or all of their services to supported employment. New service providers are also emerging to meet supported employment needs.

### **Population Issues**

The characteristics of the supported employment target population suggest that needs assessment activities should be carefully tailored to accurately identify the size, nature, and specific service needs within this population. Since the major outcome of vocational rehabilitation services has traditionally been competitive employment without ongoing support, the needs assessment for supported employment must focus on defining the service needs of persons typically not found on rehabilitation caseloads.

In comparison with a traditional vocational rehabilitation population, the following characteristics are much more likely to occur: (a) Many individuals in the target populations will have limited or no work history and limited

knowledge of work requirements and preferences, (b) some individuals will present challenging behaviors generally not tolerated in competitive employment, (c) some individuals will be nonverbal or have very limited communication skills, and (d) some individuals will exhibit very limited overall productivity (or potential for full productivity).

Among the specific service needs that are likely to emerge from the needs assessment are the following: Needs for (a) on-the-job instruction, (b) training in and arranging for and using transportation, (c) behavior management training, (d) training in break time and lunch behavior, (e) training in self-advocacy with other employees and supervisors, (f) extensive job or task restructuring, (g) very specialized job development and job placement, and (h) comprehensive situational assessments or ecological inventories. Traditional vocational rehabilitation services such as counseling and guidance and psychometric-based vocational assessment may have limited relevance for populations served through supported employment.

The application of supported employment to persons from different disability populations (e.g., mental retardation, long term mental illness, traumatic brain injury, severe and complex physical disabilities) may require different programs or combinations of services. For example, individuals with mental retardation will likely need more intensive instruction in specific job tasks than will persons with long term mental illness. Likewise, they are more likely to need more intermittent behavioral feedback and emotional support. Thus, how job development and especially job coaching are needed by different disability groups may require different professional competencies. The extent of differentiation among types of job coaching is a major dilemma for service providers in this area.

### **Service Definition Issues**

Some services that were traditionally provided at rehabilitation facilities (e.g., work adjustment training) are now provided at community job sites. In assessing the need for supported employment, it is important to differentiate it from job site training which leads to competitive employment. The programs and staff may in many cases be quite similar, but the intended outcome may be different.

### **Interagency Issues**

Vocational rehabilitation's relationship with long-term funding agencies is a critical factor in the development of supported employment. In no other service area is vocational rehabilitation so intimately linked with both provider agencies and other funding sources. While supported employment regulations do not absolutely require a commitment from a long-term funding source for support, as a condition of eligibility, early involvement in case planning with

these agencies is strongly encouraged. The long-term support funding agencies are generally county social service or human service agencies or state mental health or developmental disabilities departments. Needs assessment and planning for supported employment should be closely coordinated with these programs if capacity and resource issues are to be understood.

### **Approaches to Assessing the Need for Supported Employment**

Supported employment needs assessment is one area where interagency cooperation is most likely to occur. Because of the need for linkages between vocational rehabilitation's time-limited responsibilities and the long-term responsibilities of other agencies for funding and support for these services, coordinated or joint needs assessment efforts are appropriate. Vocational rehabilitation agencies will most likely need some involvement with state mental health and developmental disabilities agencies, education departments, and county-level human service agencies (where these are involved in purchasing supported employment services).

Many of these agencies can supply background service provision data for estimating and describing the supported employment target population. The numbers served in current long-term support vocational services (e.g., sheltered employment, work activities, and day services), in related services such as mental health community support services, and in special education can be helpful for identifying the populations. Another important area to explore with other agencies is the possibility of converting existing long-term support funding mechanisms for federal, state, and county dollars into this service.

Analysis of the extent to which supported employment has been implemented is a likely place to start the needs assessment for most vocational rehabilitation agencies. This will usually involve analyzing data submitted by provider agencies to vocational rehabilitation and to other state funding sources and administering a survey of such programs to gather more in-depth data. Such a survey can develop a database that includes (a) information on program start-up and implementation problems, (b) kinds of cases and disabilities served through the programs, (c) effective methods with different client groups, (d) service costs, (e) need for and examples of effective interagency linkages, and (e) the staff training needs for supported employment providers used by vocational rehabilitation and other funding agencies.

A survey of consumers and advocates should be an integral component of supported employment needs assessment. Such a survey would address (a) the types of jobs or job tasks currently performed by those involved in or desiring supported employment, (b) the degree of satisfaction with various jobs or tasks, (c) the kinds of jobs or tasks that still need to be located, (d) the nature and amount of on-the-job support needed (e.g., job coaching), (e) case processing

and funding barriers experienced by consumers and advocates, and (f) examples of successful supported employment practices. A major section of the survey should address issues of transportation to and from work sites, number of hours of work desired, and other services or resources needed in addition to supported employment. Individuals closed by the agency in either status 08 or 28 as "disability too severe" may be included as they are also likely candidates for supported employment.

Since supported employment represents a different approach to service provision than that which rehabilitation counselors have traditionally been involved, a vocational rehabilitation staff survey may be an important part of the needs assessment. This component could be useful in identifying the extent and nature of counselor concern about supported employment implementation and obtaining their suggestions for staff training, improved adaptation of case processing, appropriate methods for building capacity and managing cases, and for locating local resources.

As rehabilitation agencies expand their involvement in the supported employment service arena, a more systematic and customized needs assessment process may develop in coordination with other vocational service purchasers and provider agencies. The assessment of need for this service area, therefore, should be conducted in relation to the assessment of the need for rehabilitation facilities and other more traditional long-term support vocational services. Issues of relative cost, qualified staff, logistics of community-based services, hours worked, combinations with other service modalities, linkages with transportation resources and quality standards are likely to emerge from the needs assessment. They will present a unique challenge to rehabilitation agencies as they pursue further development of supported employment.

#### **Suggested Sources of Information on Need for Supported Employment**

#### **Associations and Organizations That are Resources**

Administration on Developmental Disabilities, U.S. Department of Health and Human Services, 3rd and Independence Avenues, Washington, DC 20201, (202) 245-2390.

American Association of University Affiliated Programs for Persons With Developmental Disabilities (AAUAP), 8605 Cameron St., Suite 406, Silver Spring, MD 20910, (301) 588-8252.

American Spinal Injury Association (ASIA), 250 East Superior St., Room 619, Chicago, IL 60611, (312) 908-3425.

The Association for Persons with Severe Handicaps (TASH), 7010

Roosevelt Way, NE, Seattle, WA 98115, (206) 523-8446 or 1511 King Street, Alexandria, VA 22314, (703) 683-5586.

Association for Retarded Citizens of the United States (ARC), 1522 K Street, NW, Suite 516, Washington, DC 20005, (202) 785-3388.

Association for Retarded Citizen of the United States (ARC), National Headquarters, 2501 Avenue J, Arlington, TX 76006, (817) 640-0204.

Association for Persons in Supported Employment (APSE), 5001 West Broad Street, Suite 34, Richmond, VA 23230, (804) 282-3655.

Commission on Accreditation of Rehabilitation Facilities (CARF), 101 N. Wilmot Road, Suite 500, Tucson, AZ 85711, (602) 748-1212.

Goodwill Industries of America, Inc. (GIA), 9200 Wisconsin Ave., Bethesda, MD 20814, (301) 530-6500.

International Association of Psychosocial Rehabilitation Services (IASPRS), 5550 Sterrett Place, #214, Columbia, MD 21044, (301) 730-7190.

National Association of Developmental Disability Councils, 1234 Massachusetts Avenue NW, Suite 103, Washington, DC 20005, (202) 347-1234.

National Association of Jewish Vocational Services (JVS), 101 Gary Court, Staten Island, NY 10314, (718) 370-0437.

National Association of Protection and Advocacy Systems, 900 Second Street, NE, Suite 211, Washington, DC 20002, (202) 408-9514.

National Association of Rehabilitation Facilities (NARF), P.O. Box 17675, Washington, DC 20041, (703) 648-9300.

National Association of State Mental Retardation Program Directors (NASMRPD), 113 Oronoco Street, Alexandria, VA 20025, (703) 683-4202.

National Clearing House of Rehabilitation Training Materials (NCHRTM), Oklahoma State University, 115 Old USDA Bldg., Stillwater, OK 74078, (405) 624-7650.

National Easter Seal Society (NESS), 1350 New York Avenue, NW, Suite 415, Washington, DC 20005, (202) 347-3066.

National Head Injury Foundation (NHIF), 330 Turnpike Road, Southboro, MA 01772, (508) 485-9950.

National Industries for the Severely Handicapped (NISH), 2235 Cedar Lane, Vienna, VA 22180, (703) 560-6800.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

United Cerebral Palsy Associations (UCP), 1522 K Street, #1112, Washington, DC 20005, (202) 842-1266.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

Transition Institute, School of Education, University of Illinois at Champaign, Champaign, IL 61618. Frank Rusch, Ph.D., Director, (217) 333-2325.

State developmental disabilities, mental health, and special education councils and departments, including urban and regional school district special education departments.

The 27 state change projects funded by the Rehabilitation Services Administration between 1985 and 1990. (Contact RSA for current list.)

Other resource lists for needs assessment of persons with developmental disabilities (Chapter 6), chronic mental illness (Chapter 5), traumatic brain injury (Chapter 8), and youth in transition (Chapter 11) in this volume.

Certification and professional organizations setting standards for personnel working in supported and community-based programs. For example, the Commission on the Certification of Work Adjustment

Vocational Evaluation and the Commission on Accreditation of Rehabilitation Facilities.

Association journals and the bibliographies prepared by research centers and projects are vital sources for current information on needs and methods for assessing needs.

### **Research Centers and Projects**

**Rehabilitation Research and Training Center on Improving Supported Employment Outcomes for Individuals with Developmental and Other Severe Disabilities, Virginia Commonwealth University, School of Education, MCV Box 568, Richmond, VA 23284, Paul Wehman, Ph.D., Project Director, (804) 257-1851.**

**Rehabilitation Research and Training Center for Improving the Community Integration for Persons with Mental Retardation, University of Minnesota, Department of Educational Psychology, 150 Pillsbury Drive S.E., Minneapolis MN 55455, Robert Bruininks, Ph.D., Project Director, (612) 624-5720.**

**Rehabilitation Research and Training Center on Community Integration Resource Support, Syracuse University Center on Human Policy, 4E Huntington Hall, Syracuse, NY 13210, Steven Taylor, Ph.D., Project Director, (315) 423-3851.**

**Rehabilitation Research and Training Center on Enhancing Employability of Individuals With Handicaps, University of Arkansas, 346 North West Avenue, Fayetteville, AR 72701, Vernon L. Glenn, Ed.D., Project Director, (501) 575-3656.**

**Rehabilitation Research and Training Center in Improving the Management of Rehabilitation Information Systems, West Virginia University, WV Division of Rehabilitation Services, One Dunbar Plaza, Suite E, Dunbar, WV 25064 Joseph B. Moriarty, Ph.D., Project Director, (304) 766-7138.**

**"Supported employment for chronically mentally ill," Boston University, Sargent College of Allied Health Professions, 881 Commonwealth Avenue, Boston, MA 02215, William Anthony, Ph.D., Project Director, (617) 353-3549.**

**"A national scope demonstration project for supported employment," National Association of Rehabilitation Facilities, P.O. box 17675, Washington, DC 20041. Christine Mason, Ph.D., (703) 648-9300.**

"The Employment Network," University of Oregon, 135 Education Building, Eugene, OR 97403. David Mank, Ph.D., Project Director, (503) 686-5311.

Rehabilitation Research and Training Center on Supported Employment, Virginia Commonwealth University, VCU Box 2011, Richmond, VA 23284-2011. Paul Wehman, Ph.D., Director, (804) 367-1951.

Rehabilitation Engineering Center on Modifications to Worksites and Educational Settings, Cerebral Palsy Research Foundation of Kansas, Inc., 2021 North Old Manor, Box 8217, Wichita, KS 67308. John H. Leslie, Ph.D., Project Director, (316) 688-1888.

Rehabilitation Engineering Center on the Quantification of Human Performance, Massachusetts Institute of Technology, Harvard-MIT Rehabilitation Engineering Center, 77 Massachusetts Avenue, Cambridge, MA 02139. Robert W. Mann, Sc.D., Project Director, (617) 253-0460.

Rehabilitation Engineering Center on the Quantification of Human Performance, Ohio State University, Research Foundation, 1314 Kinear Road, Columbus, OH 43212. Sheldon R. Simon, M.D., Project Director, (614) 293-8710.

### **Selected Bibliography**

Commission on Accreditation of Rehabilitation Facilities (CARF). (1991). Standards manual for organizations serving people with disabilities. Tucson, AZ: Author.

Hill, M. L. (1986). Outline and support materials to assist in the preparation of proposals to provide time-limited and on-going services within a program of supported employment. Richmond, VA: Virginia Commonwealth University, School of Education, Rehabilitation Research and Training Center.

Institute on Rehabilitation Issues. (1985). Report from the study group on supported employment: Implications for rehabilitation services. Fayetteville, AR: University of Arkansas, Arkansas Research and Training Center in Vocational Rehabilitation.

Mason, C. (1990). Effective management of supported employment. National Association of Rehabilitation Facilities. P.O. Box 17675, Washington, DC 20041.

Mason, C. (1988). Supported Employment Resource Guide, National Association of Rehabilitation Facilities, National Scope Supported Employment Demonstration Project.

Mason, C. (1989). Supported Employment In Context: NARF's National Scope Supported Employment Survey and Policy Implications, 1.

Moon, S., Goodall, P., & Wehman, P. (Eds.). (1985). Critical issues related to supported competitive employment. Richmond, VA: Virginia Commonwealth University, School of Education, Rehabilitation research and Training Center.

Moore, J. E. (1988). Report on a survey of suggested research priorities for NIDRR. Alexandria, VA: Council of State Administrators of Vocational Rehabilitation.

Policy Studies Institute. (1988). Managing supported employment costs. Rehab. Brief. Vol XI, No. 7.

Policy Studies Institute. (1987). Supported employment. Rehab. Brief. Vol. X, No. 1.

Wehman, P. (1990). A national analysis of supported employment growth and implementation. Richmond, VA: Rehabilitation Research and Training Center on Supported Employment, Virginia Commonwealth University.

Wehman, P. & Hill, J. W. (1985). Competitive employment for persons with mental retardation: From research to practice. Richmond, VA: Virginia Commonwealth University, Rehabilitation Research and Training Center.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of persons with disabilities.

The Research and Training Centers with mission related to this area.

Universities and colleges with programs concerned with training of rehabilitation, supported employment, and rehabilitation facility personnel. Particularly to be considered are those college and university programs that teach and conduct research on the use and delivery of rehabilitation services to persons with severe disabilities, developmental disabilities, and psychiatric problems.

# *Chapter 17*

## **Independent Living**

### **Background and Discussion**

During the last 25 years, public awareness and expectations for persons with severe disabilities has grown. There is now greater recognition that persons with severe disabilities can, with appropriate supports, participate more fully in all facets of life. During the 1970s, disabled advocates organized and gained sufficient strength to bring about changes in the Rehabilitation Act to establish the Independent Living Program. This authorized program of services enables persons with severe disabilities to assist themselves and each other to participate more actively in all facets of society and to exert maximum control over their own lives (Institute on Rehabilitation Issues, 1988, p. 7).

Regulations to the Rehabilitation Act require that state vocational rehabilitation agencies conduct studies of the independent living rehabilitation service needs of individuals having severe handicaps and develop plans to meet those needs. Several specific studies are mandated: Studies (a) to determine service needs in specific catchment areas of the state; (b) to compare different methods for providing required services (e.g., through regional or community centers, centers for independent living, halfway houses, and patient release programs); and (c) to determine effective alternatives to institutionalization. Any studies carried out by state agencies must fully utilize findings from relevant prior studies; the plans for the Independent Living Program must address results of these studies. They then must be addressed to and included in the agency's State Plan.

The three types of assessments mandated in the regulations to the Rehabilitation Act are discussed below. The requirements for gathering needs data for each type are discussed separately. The methods described below are examples of how the needs assessment studies might be conducted.

#### **Service Needs in Catchment Area**

This mandated needs assessment study identifies the independent living service needs of the severely disabled within the state. There are two general data gathering approaches that can be used to obtain the needs data. One general method of gathering needs assessment data is to directly survey the general population to determine the independent living service needs of the disabled population in an independent living center's catchment areas. It is important that independent living center staff and advisory board members be closely involved in the development of the survey instruments and in conducting the study. If possible, it is recommended that the independent living center conducts the survey and channels the data to the vocational rehabilitation agency for analysis. However, there are many ways that these studies can be done, and the way chosen should be based on the individual circumstances of each

situation.

The second general approach is to survey service providers to identify independent living needs from their perceptions of the direct services that are and are not being provided. This involves surveying independent living center service delivery staff on needs that are being brought to their attention by current clientele. This approach will provide needs information on (a) the types of needs that their current clientele have, (b) the relative number of persons having the various types of need, and (c) the types of services required to meet those needs. These data may also be useful for identifying gaps in services and for identifying changes taking place in client needs and services if the study is replicated at regular intervals. The vocational rehabilitation agency's program monitoring information systems can be set up to capture this type on an ongoing basis.

### **Comparative Studies of Different Methods for Providing Independent Living Services**

These mandated studies compare the effectiveness of different methods used to address independent living needs. In order to compare different service methods, it is necessary to identify the various types of service programs in the state that are providing independent living services. This would involve surveying all public and private human service agencies that are or could be involved in providing independent living services.

In conducting such surveys it is essential that a clear and understandable description of independent living services be developed to minimize confusion. The survey should be designed to identify (a) the type of service provider (e.g., community centers, halfway houses, patient release programs), (b) the types of disabilities the program serves, (c) the specific services they provide, (d) the number of persons served during a year, (e) the goals of the program, (f) the types of outcomes achieved by their clientele, (g) the number of individuals achieving those goals in a year, (h) the type of clientele and client needs their program is most effective in serving, (i) the average cost of services provided, and (j) any unmet needs and services that should be addressed by the program. Analyses of these data would enable the agency to identify the types of programs available to meet the needs brought on by various disabilities. The location of specific programs to provide those services, and gaps existing in services needed by this population.

### **Studies to Determine Effective Alternatives to Institutionalization**

The third mandated studies determine effective alternatives to institutionalization. The requirements to compare different methods of providing independent living service and to identify effective alternatives to

institutionalization would suggest that it may be necessary to survey many different human service agencies as well as seek out studies that have been conducted in the areas and integrate the results of them into the needs assessment process. These studies can take two forms: state institution surveys and secondary analyses of deinstitutionalization studies.

**State Institutions Surveys.** The first method would involve surveying state institutions to gather information on (a) the number of residents that are entering and leaving the institution annually, (b) the types of programs to which individuals are being discharged, and (c) opinions as to the types of services that would be needed in order to allow more deinstitutionalization to take place.

**Secondary Analyses of Deinstitutionalization Studies.** The second method would obtain copies of recent studies conducted by human service agencies on deinstitutionalization and on alternative methods of serving this population. Particularly relevant would be studies conducted by the human services, welfare, and developmental disabilities agencies of state government.

### **General Uses of the Assessment Results**

Although independent living programs have been funded by the federal government since 1981, they are relatively new, have limited funding, and have been unevenly implemented among the states. Individual states have been establishing programs based on sometimes rather limited understanding of independent living services and needs. Specific centers, as well, have developed service programs based on the limited understanding and diverse philosophical viewpoints of individual executive directors and consumer boards. Many of these directors and board members have had little work experience and little training or experience in managing business enterprises. Much of their energy and resources, to this point, have gone to acquiring staff and the skills needed to run these programs.

The independent living program, as a whole, is now beginning to accumulate the experience needed to develop a practical understanding of the complex array of services and outcome goals that are possible under the program. As the complexity and scope of services available through this program are recognized, the importance of assessing the independent living needs of the population served in order to identify need and distribute available resources in the most equitable manner becomes more apparent.

Many early programs for severely handicapped persons were costly and tended to create unnecessary dependence on the part of some consumers because of the full range of services provided to everyone. This program of dependence must be changed to one that provides only needed services and encourages maximum independence and self-determination. Alternative and innovative

services must be designed to enable independence among those served through independent living programs. The impacts of these alternatives need to be explored, and encouragement is needed to develop the effective service programs in order to divert people from institutionalization whenever possible.

### **Special Considerations in Assessing the Need for Independent Living Services**

There are several special considerations that need to be addressed in assessing the needs for this service:

1. A major portion of the independent living services are provided through nonprofit organizations. Personnel and advocates working with these service programs have direct contact with consumers and have developed a good understanding of independent living needs. Thus, they are an extremely valuable source for independent living service needs data.
2. It is very important that the state agency involve independent living center management and professional staff in the planning, development, and interpretation of its studies on independent living needs.
3. Some problems can be encountered in locating eligible populations when assessing the needs for independent living services. Many of the target population are being served in special programs or in institutions. They are less readily accessible through normal survey sampling techniques.
4. The needs assessment methods must be designed to accommodate or overcome severe communications and motor problems many persons with severe disabilities have if an accurate picture of independent living needs is to be obtained.

### **Suggested Sources of Information on Need for Independent Living Services**

#### **Associations and Organizations That Are Resources**

Administration on Developmental Disabilities, U.S. Department of Health and Human Services, 3rd and Independence Avenues, Washington, DC 20201, (202) 245-2390.

American Association of Retired Persons, 1909 K Street, NW, Washington, DC 20049, (202) 728-4200.

National Association for Independent Living, Fort Point Place, 27-43 Wormwood Street, Boston, MA 02210-1606, (217) 523-2587.

National Association of Protection and Advocacy Systems, 900 Second Street, NE, Suite 211, Washington, DC 20002, (202) 408-9514.

National Council on Independent Living, 2539 Telegraph Avenue, Berkeley, CA 94704, (415) 849-1243

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.

Consumer oriented associations, particularly those focused on disability and disability management.

Area independent living center programs and some rehabilitation facilities and outpatient programs at hospitals.

Nursing homes, nursing home associations, and public institutions.

State departments of human resources, or community services, and vocational rehabilitation.

### **Research Centers and Projects**

Rehabilitation Research and Training Center for Independent Living, Texas Institute for Rehabilitation and Research, P.O. Box 20095, Houston, TX 77030. Marcus J. Fuhrer, Ph.D., Project Director, (713) 799-7011.

Research and Training Center for Independent Living, 510 16th Street, Suite 100, Oakland, CA 94612. Ed Roberts, Director, (415) 763-4100.

Rehabilitation Research Training Center on Rural Rehabilitation Services, University of Montana, Missoula, MT 59812. Richard Offner, Ph.D., Project Director, (406) 243-5467.

Rehabilitation Research and Training Center on Aging and Developmental Disabilities, University Affiliated Cincinnati for

Developmental Disorders, 3300 Elland Avenue, Cincinnati, OH 45229.  
Jack Rubinstein, M.D., Project Director, (513) 559-4958.

Rehabilitation Research and Training Center on Aging, Professional Staff Association, Rancho Los Amigos Medical Center, Inc., 7600

Consuelo Street, Downey, CA 90242. Bryan J. Kemp, Ph.D., Project Director, (213) 940-7402.

Rehabilitation Research and Training Center for Rehabilitation of Elderly Disabled Individuals, University of Pennsylvania Hospital, 3400 Spruce Street, Box 590, Philadelphia, PA 19104. Stanley J. Brody, J.D., M.S.W., Project Director, (215) 662-3700.

Rehabilitation Research and Training Center in Improving the Management of Rehabilitation Information Systems, West Virginia University, WV Division of Rehabilitation Services, One Dunbar Plaza, Suite E, Dunbar, WV 25064. Joseph B. Moriarty, Ph.D., Project Director, (304) 766-7138.

Rehabilitation Engineering Center on Improved Wheelchair and Seating Design, University of Virginia Rehabilitation Engineering Center, Box 3368 University Station, Charlottesville, VA 22903. Clifford E. Brubaker, Ph.D., Project Director, (804) 977-6730.

Institute for Health and Aging, University of California, Room N631, San Francisco, CA 94143, (415) 476-2977.

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### **Existing Studies in State**

Surveys already conducted on service needs by (a) independent living centers; (b) mental hospitals, nursing homes, and other institutions; (c) private service providers (e.g., total care centers); (d) vocational rehabilitation counselors; (e) rehabilitation facilities; (f) extended employment programs (e.g., sheltered work programs); (g) private human service and welfare programs; and (h) special education programs.

Studies conducted by various public and private agencies such as (a) foundations with public service missions (e.g., Dole Foundation); (b) state, county and local agencies for welfare, housing, transportation, and disabilities; and (c) telephone companies and other municipal service providers.

Community client advocate agencies including organizations for the deaf, blind, physical, and other disabilities.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of independence and accessibility for disabled persons.

The Research and Training Centers and Rehabilitation Engineering Centers with mission areas in independent living and aging and related areas listed above. The University of Kansas developed a resource tool for conducting independent living needs assessments at the county and state levels. A source for that instrument may be found through the NIDRR or the NaRIC (listed above).

Universities and colleges with programs concerned with independent living needs and other programs that teach and conduct research on the rehabilitation of persons with severe disabilities, problems of aging, and needs for in-patient long-term services.

# *Chapter 18*

## **Rehabilitation Engineering**

### **Background and Discussion**

The 1986 Amendments to the Rehabilitation Act require that the State Plan describe how rehabilitation engineering services will be utilized (Section 202, State Plan) and include rehabilitation engineering services as an authorized vocational rehabilitation service under the basic state grant program (Section 204, Scope of Vocational Rehabilitation Services). No specific requirement for rehabilitation engineering needs assessment was identified. However, the state's needs assessment should (a) clearly distinguish between rehabilitation engineering and rehabilitation technology, (b) examine the needs for rehabilitation engineers and other resources, and (c) consider the implications that a rapidly expanding base of technology can have for serving individuals with severe disabilities.

While vocational rehabilitation agencies do not have specific federal requirements to conduct assessments of the need for rehabilitation engineering and/or technology, they will routinely be involved in this activity because they are major players in this field. P.L. 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988 and subsequent regulations (34 CFR Part 345) provide for state grants to develop consumer-responsive comprehensive statewide systems to deliver technology-related assistance to persons with disabilities. In each state, an agency will be designated by the governor to lead implementation of this effort. Vocational rehabilitation agencies, because of their responsibilities under the Rehabilitation Act, will be integrally involved in this process even if they are not the lead agency. Section 101(c)(2) states that states may conduct a statewide needs assessment and provides an extensive list of what the needs assessment may include. Applications for state grants, however, shall include a preliminary needs assessment (Section 102(e)(4)).

Needs assessment efforts are hampered by inconsistent personnel qualifications, and difficulties in acquiring uniform information on what constitutes needs for technology, assistive devices, and job accommodations. Another critical limitation is the lack of awareness by consumers of what technology is already available.

### **Definitions Issues**

There are important distinction between *Rehabilitation Engineering* and *Rehabilitation Technology*. This was discussed at length in a recent Institute on Rehabilitation Issues (1986) document on rehabilitation engineering. The IRI suggested use of the definition for rehabilitation engineering found in the Rehabilitation Reauthorization Act of 1986 (HR4021):

The term "rehabilitation engineering" means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with handicaps in areas which include education, rehabilitation, employment, transportation, independent living, and recreation (p. 1).

The Institute study group defined rehabilitation technology as "compensatory strategies and adaptive equipment used to increase functional capabilities of persons with disabilities" (p. 1). Rehabilitation engineering then refers to specialized services delivered by qualified personnel whereas rehabilitation technology refers to the equipment itself and includes low technology (e.g., reading glasses, hearing aids, crutches) as well as high technology aids (e.g., mechanized arms, computers).

### **Personnel Qualifications**

While the amendments to the Rehabilitation Act indicate that rehabilitation engineering technology and services should be provided by persons skilled in rehabilitation engineering technology, the Act does not describe the qualifications of such individuals. Any of a variety of degree and experience combinations might qualify a rehabilitation engineer, including the following: (a) a degree in engineering and rehabilitation, (b) a degree from an accredited rehabilitation engineering program or (c) a degree in engineering and a background in rehabilitation. In addition, agencies can provide training in the utilization of rehabilitation engineering technology to field staff.

### **Rapid Expansion of Technology**

The information base about rehabilitation technology is rapidly expanding and produces decision-making problems for both the client and the rehabilitation provider. With the great strides being made in medicine, orthotics, prosthetics, biomechanics, and related fields, delivery of the latest available technology to rehabilitation practitioners and their clients is critical. However, two related issues should be noted here. First, "high tech" is not always the answer to an individual's needs. Simple adaptations or accommodations may provide viable solutions to many problems encountered in rehabilitation. Identifying these (and paying for them) can be problematic in the assessment activity because they are so individualized. Second, the cost of the latest technology is often prohibitive. While such costs will decrease significantly over time and with higher volume, use of latest technology can be an inadequate basis for estimating program needs or may produce an overly ambitious effort. Some difficult judgments must be made on a case-by-case basis. Databases such as ABLEDATA can be of some assistance in making these decisions, but a qualified practitioner working with an informed client is the key to a feasible plan of action.

In a recent guide to using rehabilitation technology, prepared by the

Association for the Advancement of Rehabilitation Technology (formerly RESNA), the Association discussed a "needs analysis market study" (AART, 1987, p. 31) from the point of view of a rehabilitation technology vendor. One of the key ideas they believe should shape the needs assessment for rehabilitation engineering is that needs are assessed for more than the end-user or client. A number of persons are generally involved in the decision to purchase rehabilitation technology. They also noted the difficulty in using available statistics from the National Health Interview Survey or other sources. These sources often involve duplication of persons in various subgroups and lack specificity as to what kinds of technology might benefit what kinds of individuals.

### **Methodological Considerations**

A national survey of state agency use of rehabilitation technology was reported by the Institute on Rehabilitation Issues (1986, pp. 75-88). This was a survey covered staffing patterns, services provided and service delivery methods, sources of funding, information resources, and training needs. A great variety of approaches was found between programs. They concluded that "the ability of one individual to meet all the rehabilitation technology needs of a vocational rehabilitation agency is also unrealistic. The broad range of applications and specific expertise needed make it difficult for even broadly trained and experienced rehabilitation engineers" (p. 87). They advocated strongly for a comprehensive, interdisciplinary approach.

Employer responsibility as defined by the Americans with Disability Act should act to create a market for accommodation services and a need for awareness of the benefits of rehabilitation technology on the part of employers. Surveys of employers can serve to validate the existence of this market. The behavior of state rehabilitation agencies and rehabilitation facilities can act to nurture this market or ignore its potential if the employer is not seen as a potential client as well.

Identification of the target population in need and then sampling them will prove difficult for a variety of reasons. Depending on the scope of rehabilitation engineering that a vocational rehabilitation agency determines, the target population may be less than three percent of the total American population, making sampling of the general population rather inefficient. Secondly, needs may not be known by individuals unless a functionally-based assessment has been conducted with the individual. A small, carefully selected sample of current or potential rehabilitation engineering service recipients might provide a respectable initial estimate of the kinds and scope of rehabilitation engineering needs that might be required of the state's unit.

The analysis of rehabilitation engineering service needs data should have  al implications for the general program. Extent of need, given the potential

cost of engineering, might suggest a need to implement an order of selection for the state agency's engineering services. Needs identified in the rehabilitation engineering area may also tend to suggest a rationale for a general order of selection for prioritizing services to persons with severe handicaps.

With both the rapid advances in rehabilitation technology and the evolution of rehabilitation as a discipline, needs assessment in the rehabilitation engineering field must be seen as developmental. As with rehabilitation in general, the scope of the activities and the definition of the target population need to be refined. As refinement proceeds, more "models" of needs assessment will be available. One method that will result in awareness of what resources exist is the development of a "resource grid" which is most useful if developed first at the local level and collected and disseminated at a statewide level. This approach has the immediate benefit of plugging knowledge gaps on the part of rehabilitation agency service providers who can share this knowledge with consumers.

With the passage of the Technology-Related Assistance Act, interagency efforts are developing at the state level that will include assessment of the need for rehabilitation technology services, including those provided by vocational rehabilitation under the Rehabilitation Act. At this point, many states are inventorying resources and trying to organize them to be more efficient in service delivery. Key informant surveys and public forums are useful vehicles to address needs in this area.

### **Special Considerations in Assessing the Need for Rehabilitation Engineering**

1. The rapid development of technology is itself a problem in assessing the need for rehabilitation engineering. End-users and service providers are involved in decisions about adaptive devices. Neither may be fully aware of the technology available to meet their needs. The assessment efforts could profitably address needs from both client and service provider perspectives.
2. A carefully selected sample of current and recent rehabilitation clients, including those who have received or were potential rehabilitation engineering service recipients, can provide basic information on the types and scope of needs the agency is presently addressing. The sample would need to be representative of the populations that the state anticipates serving through its engineering unit. Reviews of the case records for this sample, or follow-up interviews with them, may also help to identify some needs that could be addressed by the agency.
3. Special cautions must be included when seeking rehabilitation engineering needs data, especially from persons not served by rehabilitation. Whether

in an interview or a survey format, questions that ask about functional impairments, rather than need for various types of devices, will provide more useful data for agency planning. These types of data can help the agency understand the potential scope of needs and resources the agency might have to develop or locate.

4. Alternative methods may need to be employed in acquiring needs information from persons with different disabilities. Some individuals may need to be contacted by TDD, others would need large print or taped versions of any written questionnaires, and others may need assistance in responding due to lack of clarity of speech.

#### **Suggested Sources of Information on Need for Rehabilitation Engineering**

#### **Associations and Organizations That Are Resources**

ABLEDATA, Adaptive Equipment Center, Newington Children's Hospital, 181 East Cedar Street, Newington, CT 06111, (800) 344-5405.

Association for the Advancement of Rehabilitation Technology (AART or RESNA), 1101 Connecticut Avenue NW, Suite 700, Washington, DC 20036, (202) 857-1199.

CO-NET, University of Wisconsin-Madison, Trace Center, 750 University Avenue, Madison, WI 53706, (608) 262-3822.

ERIC Distribution Resource Service, 3900 Wheller Avenue, Alexandria, VA 22304-6409, (800) 227-3742.

Health Services and Research Administration, Department of Veterans Affairs, 810 Vermont Avenue, NW, Washington, DC 20420, (202) 233-2300.

National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, DC 20202-2572, (202) 732-1192.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-

1294.

### **Research Centers and Projects**

Rehabilitation Research and Training Center in Independent Living, TIRR, 1333 Moursund Avenue, Houston, TX 77030. Marcus J. Fuhrer, Ph.D., Project Director, (713) 799-7011.

Rehabilitation Research and Training Center on New Directions for Rehabilitation Facilities, University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, School of Education and Human Services, Menomonie, WI 54751. Daniel C. McAlees, Ph.D., Project Director, (715) 232-1389.

Rehabilitation Research and Training Center on Enhancing Employability of Individuals With Handicaps, University of Arkansas, 346 North West Avenue, Fayetteville, AR 72701. Vernon L. Glenn, Ed.D., Project Director, (501) 575-3656.

Rehabilitation Research and Training Center on Rural Rehabilitation Services, University of Montana, 33 Corbin Hall, Missoula, MT 59812. Richard B. Offner, Ph.D., Project Director, (406) 243-5467.

Rehabilitation Research and Training Center in Improving the Management of Rehabilitation Information Systems, West Virginia University, WV Division of Rehabilitation Services, One Dunbar Plaza, Suite E, Dunbar, WV 25064. Joseph B. Moriarty, Ph.D., Project Director, (304) 766-7138.

Rehabilitation Engineering Center for Rehabilitation Technology Resources, New England Association for Business, Industry, and Rehabilitation, Inc., 25 Science Park, New Haven, CT 06511. Carl V. Puleo, Project Director, (203) 786-5565.

Rehabilitation Engineering Center on Evaluation of Rehabilitation Technology, National Rehabilitation Hospital, Rehabilitation Engineering Services, 102 Irving Street, NW, Washington, DC 20010. Samuel McFarland, Ph.D., Project Director, (202) 877-1932.

Rehabilitation Engineering Center for the Delivery of Cost Effective Rehabilitation Engineering Services, South Carolina Vocational Rehabilitation Department, Office of the Commissioner, P.O., Box 15, West Columbia, SC 29171. Anthony Langton, Project Director, (803) 734-5301.

Rehabilitation Engineering Center on Improved Wheelchair and Seating

Design, University of Virginia, Rehabilitation Engineering Center, Box 3368 University Station, Charlottesville, VA 22903. Clifford E. Brubaker, Ph.D., Project Director, (804) 977-6730.

Rehabilitation Engineering Center on Access to Computers and Electronic Equipment, University of Wisconsin-Madison, Trace Center, 750 University Avenue, Madison, WI 53706. Gregg Vanderheiden, Ph.D., Project Director, (608) 262-3822.

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Rehabilitation Research Institute. (1979, July). Impact matches problems with available rehabilitation technology. Rehab Brief, II(5). Gainesville, FL: Author.

Rehabilitation Research Institute. (1981, August). Assistive devices. Rehab Brief, IV(9). Gainesville, FL: Author.

RESNA, Association for the Advancement of Rehabilitation Technology. (1987). Rehabilitation technology service delivery: 1. A practical guide. Washington, DC: Author.

### **Existing Studies**

Studies of needs conducted by such service providers as (a) independent living centers; (b) residential institutions and nursing homes; (c) vocational rehabilitation counselors; (d) rehabilitation facilities; (f) extended employment programs (e.g., sheltered work programs); (g) veterans administration hospitals; and (h) special education programs.

Studies of technology and accommodations conducted by various public

and private agencies as (a) state, county and local agencies (e.g., transportation, housing, public health); (b) businesses providing consumer services (e.g., telephone companies, hotel and restaurant associations, discount and department store chains, computer companies and associations); and (c) employers hiring or accommodating individuals with disabilities.

Community client advocate agencies including organizations for the deaf, blind, physical and other disabilities.

### **Standard Resources for Assistance**

Community action, advocacy, religious, and service delivery agencies and organizations working on behalf of independence and accessibility for disabled persons. Businesses with public service goals and user-groups, especially in the area of computer applications, may be included.

The Rehabilitation Engineering Centers with either (a) a goal to identify technology for state agency clients or (b) a goal to find broader applications of existing and emerging technology.

The Research and Training Centers, especially those with mission areas of independent living and employment.

Universities and colleges with programs concerned with rehabilitation technology, rehabilitation engineering, or independent living needs and other programs that teach and conduct research on the rehabilitation of persons with engineering needs or persons with severe disabilities and problems of aging.

# *Appendices*

## **Resources Useful for Conducting Statewide Comprehensive Needs Assessment**

- A. Bibliography for Volume II**
- B. Suggested Texts and Methods Materials**
- C. Suggested Format for the Needs Assessment Report**
- D. Clearing Houses and Secondary Data Sources**
- E. Rehabilitation Research and Training Centers**
- F. Spinal Cord Centers**
- G. Traumatic Brain Injury Centers**
- H. Rehabilitation Engineering Centers**
- I. Regional Continuing Education Programs**
- J. Selected Federal Agencies**
- L. Consumer and Advocacy Organizations**
- M. Facility Associations**

**A. Bibliography for Volume II**

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### B. Suggested Texts and Methods Materials

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### **C. Suggested Format for the Needs Assessment Report**

**Executive Summary.** Brief overview of the study. In a very few pages (e.g., two pages) the objectives, findings, implications for agency policy and program development, and the specific recommendations are summarized.

**Description of Study.** Direct statements of purposes for the study, its objectives or assessment questions, and the context in which the study was conceived, designed, and conducted.

**Methodology.** Outline of significant data sources (instrumentation, samples), how representative needs data were identified and collected, the extent and quality of the data used in the assessment, and the general precautions and procedures used to synthesize the data and address the questions and objectives of the study.

**Results and Findings.** Declarative presentation of answers to the questions and objectives of the assessment. Included as supplemental to which finds are any limitations imposed by quality of the data and the representativeness of samples and subsamples. Tabular and graphic presentations should be used to enhance the understandability of the results.

**Implications and Recommendations.** Direct extrapolations of meaning from the results and findings. Implications should translate findings about need into potential effects on or changes in legislation, policy, administrative actions, program, and resource allocations. Recommendations should suggest options and actions which the agency should and can pursue to meet the identified needs.

**Appendices.** Appendices should be included with caution. They should include a list of staff and non-agency stakeholders on the assessment taskforce, a list of supplemental reports or summaries available on the assessment, and, if necessary, a minimum of supportive information and reference.

#### **D. Clearing Houses and Secondary Data Sources**

##### **Clearing Houses**

ABLEDATA, Adaptive Equipment Center, Newington Children's Hospital, 181 East Cedar Street, Newington, CT 06111, (800) 344-5405.

CO-NET, Trace Research and Development Center, 1500 Highland Avenue, Madison, WI 53705.

Materials Development Center (MDC), Stout Vocational Rehabilitation Institute, University of Wisconsin-Stout, Menomonie, WI 54751, (715) 232-2419.

National Clearing-House of Rehabilitation Training Materials (NCHRTM), Oklahoma State University, 115 Old USDA Bldg., Stillwater, OK 74078, (405) 879-7650.

National Rehabilitation Information Center (NaRIC), 8455 Colesville Rd., Suite 935, Silver Spring, MD 20910-3319, (800) 346-2742.

Institute for Health and Aging, University of California, Room N631, San Francisco, CA 94143, (415) 476-2977.

##### **Where Sources of Data Exist**

U.S. Census Bureau and the U.S. Department of Labor.

U.S. Department of Education. (1986, June). Directory of National Information Sources on Handicapping Conditions and Related Services. Washington, DC: Office of Special Education and Rehabilitative Services, National Institute of Handicapped Research.

State Employment Service Agencies, Labor Market, Research and Statistics Sections.

State Developmental Disability Agencies or Councils.

National Association of Developmental Disability Councils, 1234 Massachusetts Avenue NW, Suite 103, Washington, DC 20005, (202) 347-1234.

International Center for the Disabled, 340 E. 24th Street, New York, NY 10010.

University of Michigan Survey Research Institute.

**Major Reports Publications**

National Health Survey.

University Studies.

Consumer Advocacy Groups, Reports and Studies.

Other States Vocational Rehabilitation Agency Studies.

### **E. Rehabilitation Research and and Training Centers**

Centers are funded by the National Institute on Disability and Rehabilitation Research, in the Office of Special Education and Rehabilitation Services, U.S. Department of Education.

**Center on Aging and Developmental Disabilities, University Affiliated Cincinnati for Developmental Disorders, 3300 Elland Avenue, Cincinnati, OH 45229. Jack Rubinstein, M.D., Project Director, (513) 559-4958.**

**Center on Aging, Professional Staff Association, Rancho Los Amigos Medical Center, Inc., 7600 Consuelo Street, Downey, CA 90242. Bryan J. Kemp, Ph.D., Project Director, (213) 940-7402.**

**Center for Rehabilitation of Elderly Disabled Individuals, University of Pennsylvania Hospital, 3400 Spruce Street, Box 590, Philadelphia, PA 19104. Stanley J. Brody, J.D., M.S.W., Project Director, (215) 662-3700.**

**Center on Arthritis, University of Missouri-Columbia, 501 Rusk Center, One Hospital Drive, Columbia, MO 65212. Paul Kaplan, M.D., Project Director, (314) 882-3101.**

**Center on Blindness and Low Vision, Mississippi State University, P.O. Drawer 6189, Mississippi State, MS 39762. William H. Graves, Ed.D., Project Director, (601) 325-2201.**

**Center on Families and Disability, Beach Center, University of Kansas, Bureau of Child Research, 2045 Haworth Hall, Lawrence, KS 66045. Ann P. Turnbull, Ed.D., Co-Project Director; H. Rutherford Turnbull, L.L.B., L.L.M., Co-Project Director, (913) 864-4295.**

**Center in Child Trauma, Tufts-New England Medical Center, Department of Rehabilitation Medicine, 750 Washington Street, Box 75K/R, Boston, MA 02111. Stephen M. Haley, Ph.D., Project Director, (617) 956-5031.**

**Center in Pediatrics, University of Connecticut Health Center, Department of Pediatrics, Division of Child and Family Studies, The Exchange, Suite 164, 170 Farmington Avenue, Farmington, CT 06032. Mary Beth Bruder, Ph.D., Project Director, (203) 674-1485.**

**Center on Children's Mental Health, University of South Florida, Florida Mental Health Institute, 13301 Bruce D Downs Boulevard, Tampa, FL 33612. Robert M. Friedman, Ph.D., Project Director, (813) 974-4500.**

**Center on Improving Services for Seriously Emotionally Handicapped Children**

and Their Families, Portland State University, Regional Research Institute for Human Services, P.O. Box 751, Portland, OR 97207-0751. Barbara Friesen, Ph.D., Project Director, (503) 464-4040.

Center on Community Integration Resource Support, Syracuse University, Center on Human Policy, 724 Comstock Avenue, Syracuse, NY 13244-4230. Steven J. Taylor, Ph.D., Project Director, (315) 443-3851.

Center on Community Living, University of Minnesota, 101 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. Robert H. Bruininks, Ph.D., Project Director, (612) 625-3396.

Center for Community-Referenced Technologies for Nonadversive Behavior Modification, University of Oregon, Center on Human Development, 135 Education Building, Eugene, OR 97403. Robert H. Horner, Ph.D., Project Director, (503) 686-5311.

Center on Mental Health Rehabilitation of Individuals With Deafness, University of California-San Francisco, Center for Deafness, 3333 California Street, Suite 10, San Francisco, CA 94143. Laurel E. Glass, MD, Ph.D., Project Director, (415) 476-4980.

Center on Vocational Rehabilitation of Individuals With Deafness and Hearing Impairments, University of Arkansas, 4601 West Markham, Little Rock, AR 72205. Douglas Watson, Ph.D., Project Director, (501) 371-1654.

Center for Access to Rehabilitation and Economic Opportunity, Howard University, School of Education, 2900 Van Ness Street, NW, Washington, DC 20008. Sylvia Walker, Ed.D., Project Director, (202) 686-6726.

Center on Enhancing Employability of Individuals With Handicaps, University of Arkansas, 346 North West Avenue, Fayetteville, AR 72701. Vernon L. Glenn, Ed.D., Project Director, (501) 575-3656.

Center on Improving Supported Employment Outcomes for Individuals With Developmental and Other Severe Disabilities, Virginia Commonwealth University, School of Education, 1314 West Main Street, VCU Box 2011, Richmond, VA 23284-2011. Paul H. Wehman, Ph.D., Project Director, (804) 367-1851.

Center on American Indian, Northern Arizona University, Institute for Human Development, P.O. Box 5630, Flagstaff, AZ 86011-5630. Marilyn J. Johnson, Ph.D., Project Director, (602) 523-4791.

Center for Native Americans, University of Arizona, 1642 East Helen Street, Tucson, AZ 85719. Jennie R. Joe, Ph.D., Project Director, (602) 621-5075.

Center for Pacific Basin Rehabilitation, University of Hawaii at Manoa, John A. Burns School of Medicine, 266 North Kuakini Street, Suite 233, Honolulu, HI 96817. Daniel D. Anderson, Ed.D., Director, (808) 537-5986.

Center on Rural Rehabilitation Services, University of Montana, 33 Corbin Hall, Missoula, MT 59812, Richard B. Offner, Ph.D., Project Director, (406) 243-5467.

Center on New Directions for Rehabilitation Facilities, University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, School of Education and Human Services, Menomonie, WI 54751. Daniel C. McAlees, Ph.D., Project Director, (715) 232-1389.

Center in Independent Living, TIRR, 1333 Moursund Avenue, Houston, TX 77030. Marcus J. Fuhrer, Ph.D., Project Director, (713) 799-7011.

Center on Independent Living, University of Kansas, Bureau of Child Research, 3111 Haworth Hall, Lawrence, KS 66045. James F. Budde, Ed.D., Project Director, (913) 864-4095.

Center in Improving the Management of Rehabilitation Information Systems, West Virginia University, WV Division of Rehabilitation Services, One Dunbar Plaza, Suite E, Dunbar, WV 25064. Joseph B. Moriarty, Ph.D., Project Director, (304) 766-7138.

Center on Multiple Sclerosis, Yeshiva University, Albert Einstein College of Medicine, 1300 Morris Park Avenue, Bronx, NY 10461. Labe Scheinberg, M.D., Project Director, (212) 430-2682.

Center on Neural Recovery and Functional Enhancement, Jefferson Medical College of Thomas Jefferson University, 111 South 11th Street, Philadelphia, PA 19107. John F. Ditunno, Jr., M.D., Project Director, (215) 928-6573.

Center in Progressive Neuromuscular Diseases, University of California-Davis, School of Medicine, TB 191, Dept. of Physical Medicine and Rehabilitation, Davis, CA 95616. William M. Fowler, Jr., M.D., Project Director, (916) 752-2903.

Center for Psychiatric Rehabilitation, Center for Psychiatric Rehabilitation, 730 Commonwealth Avenue, Boston, MA 02215. William A. Anthony, Ph.D., Project Director, (617) 353-3549.

Center for Psychiatrically Disabled Individuals, Yeshiva University, Albert Einstein College of Medicine, 1300 Morris Park Avenue, Bronx, NY 10461. Labe Scheinberg, M.D., Project Director, (212) 430-2682.

Center in Community-Oriented Services for Persons With Spinal Cord Injury, Baylor College of Medicine, Department of Rehabilitation Medicine, 1333 Moursund Avenue, Houston, TX 77030. Marcus J. Fuhrer, Ph.D., Project Director, (713) 799-7011.

Center in Prevention and Treatment of Secondary Complications of Spinal Cord Injury, University of Alabama at Birmingham, Department of Rehabilitation Medicine, University Station, Birmingham, AL 35294. Samuel L. Stover, M.D., Project Director, (205) 934-3330.

Center for Treatment and Prevention of Secondary Complications of Spinal Cord Injury, Northwestern University, Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, IL 60611. Henry B. Betts, M.D., Project Director, (312) 908-6017.

Center for Community Integration of Persons With Traumatic Brain Injury, State University of New York at Buffalo, 197 Farber Hall, 3435 Main Street, Buffalo, NY 14214. John H. Noble, Jr., Ph.D., Project Director, (716) 636-3381.

Center of Traumatic Brain Injury and Stroke, New York University Medical Center, Department of Rehabilitation Medicine, 400 East 34th Street, New York, NY 10016. Leonard Diller, Ph.D., Project Director, (212) 340-6161.

Center in Traumatic Brain Injury, University of Washington, Department of Rehabilitation Medicine, BB-919 Health Sciences Building, Seattle, WA 98195. Justin F. Lehmann, M.D., Project Director, (206) 543-6766.

Center in Traumatic Brain Injury, Virginia Commonwealth University, Medical College of Virginia, Box 434, MCV Station, Richmond, VA 23298-0434. Henry H. Stonnington, Project Director, (804) 786-0231.

Center for Rehabilitation of Long-Term Mental Illness, Threshold Research Institute, 561 Diversey parkway, Suite 210A, Chicago, IL 60614. Judith Cook, Ph.D., (312) 348-5522.

#### **F. Spinal Cord Centers**

Model Spinal Cord Injury System, Spain Rehabilitation Center, University of Alabama/Birmingham, Samuel L. Stover, M.D., University Station, SRC-520, Birmingham, AL 32594, (205) 934-3330

Model Spinal Cord Injury System, Rancho Los Angeles Medical Center, Robert Waters, M.D., 7413 Golondrinas Street, Downey, CA 90242, (213) 940-1115.

Model Spinal Cord Injury System, Rocky Mountain Science Center, Craig Hospital, 3425 Clarkson Street, Englewood, CO 80110, (303) 789-8214.

Model Spinal Cord Injury System, Sheperd Center for Treatment of Spinal Injuries, David F. Apple, Jr., M.D., 2020 Peachtree Road NW, Atlanta, GA 30309, (404) 355-9772.

Model Spinal Cord Injury System, Northwestern Memorial Hospital, Northwestern Memorial Medical Center, Paul R. Meyer, Jr., M.D., 250 E. Chicago Avenue, Suite 619, Chicago, IL 60611, (312) 908-3425.

Model Spinal Cord Injury System, New England Regional Spinal Injury Center, Boston University, Murray Freed, M.D., 88 East Newton Street, Boston, MA 02118, (617) 638-7300.

Model Spinal Cord Injury System, Rehabilitation Institute of Detroit, Wayne State University, Saul Weingarden, M.D., 261 Mack Blvd., Detroit, MI 48201, (313) 745-9770.

Model Spinal Cord Injury System, Department of Physical Medical and Rehabilitation, University of Mighigan, Frederick Maynard, M.D., N12A09-0491 300, North Ingalls BG, Ann Arbor, MI 48109, (313) 936-7210.

Model Spinal Cord Injury System, Institute of Rehabilitation Medicine, New York University Medical Center, Ahn Jung, M.D., 400 E. 34th St., New York, NY 10016, (212) 340-6122.

Model Spinal Cord Injury System, Strong Memorial Hospital, University of Rochester Medical Center, Charles J. Gibson, M.D., 601 Elmwood Avenue, Rochester, NY 14642.

Model Spinal Cord Injury System, Thomas Jefferson Medical College, Thomas Jefferson University, John F. Ditunno, Jr., M.D., 11th and Walnut Streets, Philadelphia, PA 19107, (215) 928-6579.

Model Spinal Cord Injury System, Institute for Rehabilitation and Research, Texas Medical Center, R.E. Carter, M.D., 1333 Moursund Avenue, Houston,

TX 77030, (713) 797-5910.

Model Spinal Cord Injury System, Orthopedics & Rehabilitation, University of Virginia Medical Center, Warren G. Stamp, M.D., Box 426, Charlottesville, VA 22904, (804) 924-8577.

## **G. Traumatic Brain Injury Centers**

### **Regional Centers**

The four Regional Centers are funded by the Rehabilitation Services Administration, Office of Special Education and Rehabilitation Services, U.S. Department of Education.

Midwest Regional Head Injury Center for Rehabilitation and Prevention, Rehabilitation Institute of Chicago, 345 E. Superior, Chicago, IL 60611. Henry B. Betts, M.D., Director, (312) 908-6017.

Rocky Mountain Head Injury Center, Colorado Rehabilitation Services, Facilities Grants and Independent Living, 1575 Sherman Street, 4th Floor, Denver, CO 80203. Richard Parsons, Director, (303) 866-6024.

Southwest Regional Comprehensive Brain Injury Rehabilitation and Prevention Center, The Institute for Rehabilitation and Research, Brain Injury Program, 1333 Moursund Avenue, Houston, TX 77030. L. Don Lehmkuhl, Ph.D., Director, (713) 797-5713.

Comprehensive Regional Traumatic Brain Injury Rehabilitation and Prevention Center, Mount Sinai Medical Center, One Gustav Levy Place, New York, NY 10029. Wayne A. Gordon, Ph.D., Director, (212) 241-7917.

### **Model Systems Projects**

The Model Systems Projects are funded by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitation Services, U.S. Department of Education.

A comprehensive system of care for traumatic brain injury, Institute for Medical Research, Santa Clara County, 2260 Clove Street, San Jose, CA 95128. Jeffrey Englander, M.D., Project Director, (408) 257-7538.

A Model System for Minimizing Disabilities After Head Injury, Institute for Rehabilitation and Research, 1333 Moursund Avenue, Houston, TX 77030. Catherine Bantke, M.D., Project Director, (713) 799-7011.

Model Project for Comprehensive Rehabilitation Services to Individuals with Traumatic Brain Injury, Mt. Sinai Medical Center, School of Medicine, One Gustave L. Levy Place, New York, NY 10029. Kristjan Ragnarsson, M.D., Project Director, (212) 650-6335.

A Comprehensive Model of Research and Rehabilitation for the Traumatically Brain Injured, Virginia Commonwealth University, Medical College of Virginia, Box 568 MCV Station, Richmond, VA 23298. Jeffrey Kruetzer, Ph.D., Project Director, (804) 786-0200.

South Eastern Michigan Traumatic Brain Injury System, Wayne State University, Department of Neurology, Detroit, MI 48202. Mitch Rosenthal, Ph.D., Project Director, (202) 732-1192.

## **H. Rehabilitation Engineering Centers**

Rehabilitation Engineering Centers are funded by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitation Services, U.S. Department of Education.

Center on Development and Evaluation of Sensory Aids for Blind and Deaf, Smith-Kettlewell Institute of Visual Sciences, 2232 Webster Street, San Francisco, CA 94115. Arthur Jampolsky, M.D., Project Director, (415) 561-1630.

Center for Rehabilitation Technology Resources, New England Association/Bus Ind and Rehabilitation, Inc., 25 Science Park, New Haven, CT 06511. Carl V. Puleo, Project Director, (203) 786-5565.

Center on Augmentative Communication Devices, University of Delaware, Department of Computer and Information Science, Newark, DE 19711. Richard Foulds, Ph.D., Project Director, (302) 451-2712.

Center on Evaluation of Rehabilitation Technology, National Rehabilitation Hospital, Rehabilitation Engineering Services, 102 Irving Street, North West, Washington, DC 20010. Samuel McFarland, Ph.D., Project Director, (202) 877-1932.

Center in Prosthetics and Orthotics, Northwestern University, Rehabilitation Engineering Program, 633 Clark Street, Evanston, IL 60208. Dudley S. Childress, Ph.D., Project Director, (312) 908-8560.

Center on Modifications to Worksites and Educational Settings, Cerebral Palsy Research Foundation of Kansas, Inc., 2021 North Old Manor, Box 8217, Wichita, KS 67203. John H. Leslie, Ph.D., Project Director, (316) 688-1888.

Center on the Quantification of Human Performance, Massachusetts Institute of Technology, Harvard-MIT Rehabilitation Engineering Center, 77 Massachusetts Avenue, Cambridge, MA 02139. Robert W. Mann, SC.D., Project Director, (617) 253-0460.

Center on the Quantification of Human Performance, Ohio State University, Research Foundation, 1314 Kinear Road, Columbus, OH 43212. Sheldon R. Simon, M.D., Project Director, (614) 293-8710.

Center on Technological Aids for Deaf and Hearing Impaired Individuals, The Lexington Center, Incorporated, Research and Training Division, 30th and 75th Street, Jackson Heights, NY 11370. Harry Levitt, Project Director, (718) 899-8800, extension 230.

Center for the Delivery of Cost Effective Rehabilitation Engineering Services, South Carolina Vocational Rehabilitation Department, Office of the Commissioner, Post Office Box 15, West Columbia, SC 29171. Anthony Langton, Project Director, (803) 734-5301.

Center in Low Back Pain (LBP), University of Vermont, Department of Orthopedics and Rehabilitation, 1 South Prospect Street, Burlington, VT 05404. John W. Brymoyer, M.D., Project Director, (802) 656-4067.

Center on Improved Wheelchair and Seating Design, University of Virginia, Rehabilitation Engineering Center, Box 3368 University Station, Charlottesville, VA 22903. Clifford E. Brubaker, Ph.D., Project Director, (804) 977-6730.

Center on Access to Computers and Electronic Equipment, University of Wisconsin-Madison, Trace Center, 750 University Avenue, Madison, WI 53706. Gregg Vanderheiden, Ph.D. Project Director, (608) 262-3822.

## I. Regional Continuing Education Programs

**Regional Continuing Education Programs (RCEP)** are funded by the Rehabilitative Services Administration, Office of Special Education and Rehabilitation Services, U.S. Department of Education.

**Region I RCEP**, Institute for Social and Rehabilitation Services, Assumption College, 500 Salisbury St., Worcester, MA 01609. George S. Elias, Director, (617) 755-0677.

**Region II RCEP**, Department of Counseling and Education Psychology, State University of New York at Buffalo, 311 Christopher Baldy Hall, Buffalo, NY 14260. Dwight R. Kauppi, Director, (716) 636-2476.

**Region III RCEP**, The George Washington University, 2021 K Street, NW, Suite 211, Washington, DC 20052. Donald W. Dew, Director, (202) 676-5929.

**Region IV RCEP**, University of Tennessee, 337 Claxton Addition, Knoxville, TN 37996-3400. James H. Miller, Director, (615) 974-8111.

**Region V RCEP**, 300 East Main Street, Suite 16, Carbondale, IL 62901. Dave Adams, Director, (618) 536-2461.

**Region VI RCEP**, University of Arkansas, P.O. Box 1358, Hot Springs, AR 71901. Leon Thornton, Director, (501) 624-4411 ext. 315.

**Region VII RCEP**, University of Missouri-Columbia, 105 E. Ash St., Suite 100, Columbia, MO 65203. C. David Roberts, Director, (314) 3807.

**Region VIII RCEP**, College of Health and Human Services, McKee Hall, Room 44, University of Northern Colorado, Greeley, CO 80639. Raymond Nelson, Director, (303) 351-2159.

**Region IX RCEP**, San Diego State University, 6361 Alvarado Court, San Diego, CA 92120. Fred R. McFarlane, Director, (619) 594-4220.

**Region X RCEP**, Seattle University, 12th and East Columbia, Seattle, WA 98122. Colleen Fox, Director, (206) 626-5783.

### **J. Selected Federal Agencies**

**Administration on Developmental Disabilities, U.S. Department of Health and Human Services, 3rd and Independence Avenues, Washington, DC 20201, (202) 245-2390.**

**National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education, 400 Maryland Ave., SW, Washington, D.C. 20202-2572, (202) 732-1192.**

**Rehabilitation Services Administration (RSA), Office of Special Education and Rehabilitative Services, U.S. Department of Education, Switzer Bldg., 330 C St., SW, Washington, DC 20202, (202) 732-1294.**

**Region I, John Szufnarowski, RSA Regional Commissioner, Department of Education, OSERS, John F. Kennedy Federal Building, Room E 400, Government Center, Boston, MA 02203, (617) 565-2637.**

**Region II, John Conti, Ph.D., RSA Regional Commissioner, Department of Education, OSERS, 26 Federal Plaza, Room 4104, New York, NY 10278, (212) 264-4016.**

**Region III, Ralph Pacinelli, Ph.D., RSA Regional Commissioner, Department of Education, OSERS, 3535 Market Street, Room 16120, Philadelphia, PA 19104, (215) 596-0317.**

**Region IV, Tamara Bibb, RSA Regional Commissioner, Department of Education, OSERS, 101 Marietta Street, North West, Suite 2210, Post Office Box 1691, Atlanta, GA 30301, (404) 331-2352.**

**Region V, Terry Conour, RSA Regional Commissioner, Department of Education, OSERS, 401 South State Street, Suite 700E, Chicago, IL 60605-1202, (312) 886-5372.**

**Region VI, Harold Vialle, RSA Regional Commissioner, Department of Education, OSERS, 1200 Main Tower Building, Room 2140, Dallas, TX 75202, (214) 767-2961.**

**Region VII, Isaac Johnson, RSA Regional Commissioner, Department of Education, OSERS. Post Office Box 901381, Kansas City, MO 64190-1381, (816) 891-8015.**

Region VIII, James Dixon, Acting RSA Regional Commissioner, Department of Education, OSERS, Federal Office Building, Room 398, 1961 Stout Street, Denver, CO 80294, (303) 844-2135.

Region IX, Gilbert Williams, Acting RSA Regional Commissioner, Department of Education, OSERS, Federal Office Building, Room 229, 50 United Nations Plaza, San Francisco, CA 94102, (415) 556-7333.

Region X, William Bean, Ph.D., RSA Regional Commissioner, Department of Education, OSERS, 915 Second Avenue, Room 3390, Seattle, WA 98174-1099, (206) 442-5331.

U.S. Department of Labor, 200 Constitution Ave., NW, Washington, DC 20210, (202) 523-7316.

Veteran's Health Services and Research Administration, Dept. of Veteran's Affairs, 810 Vermont Ave. N, Washington, D.C. 20420. John A. Gronvall, M.D., Chief Medical Director, (202) 233-2300.

National Institute on Aging, 9000 Rockville Pike, Bldg. 31, Room 2002, Bethesda, MD 20892. P.S. Williams, M.D., Director, (301) 496-5345.

Housing and Urban Development Dept., Intergovernmental Relations, HUD Building, 451 7th St., SW, Washington, DC 20410, (202) 735-6980.

U.S. Department of Transportation, 400 7th St., SW, Washington, DC 20590, (202) 366-5580.

U.S. Department of Health and Human Services, 200 Independence Ave., SW, Washington, DC 20201.

### **K. Consumer and Advocacy Organizations**

**Adaptive Environments Center, Massachusetts College of Art, 621 Huntington Avenue, Boston, MA 02115, (617) 739-0088 (Voice and TDD).**

**American Amputee Foundation, Inc. (AAF), Box 55218, Little Rock, AR 72225, (501) 666-2523.**

**American Cancer Society (ACS), 90 Park Avenue, New York, NY 10016, (212) 599-8200.**

**American Coalition of Citizens with Disabilities (ACCD), 1012 14th Street, North West, Suite 901, Washington, DC 20005, (202) 628-3470.**

**American Council of the Blind (ACB), Suite 110, 1010 Vermont Avenue, North West, Washington, DC 20005, (202) 393-3666, (800) 424-8666.**

**American Foundation for the Blind (AFB), 15 West 16th Street, New York, NY 10011, (212) 620-2000.**

**American Heart Association (AHA), 7320 Greenville Avenue, Dallas, TX 75231, (214) 750-5300.**

**American Lung Association (ALA), 1740 Broadway, New York, NY 10019, (212) 315-8700.**

**American Society for Deaf Children (ASDC), 814 Thayer Avenue, Silver Springs, MD 20910, (301) 585-5400.**

**Arthritis Foundation, 1314 Spring Street, North West, Atlanta, GA 30309, (404) 872-7100.**

**Association for Children and Adults with Learning Disabilities (ACLD), 4156 Library Road, Pittsburgh, PA 15234, (412) 341-1515, (412) 341-8077.**

**Association for Persons with Severe Handicaps (TASH), 7010 Roosevelt Way, North East, Seattle, WA 98115, (206) 523-8446.**

**Association for Retarded Citizens of the United States (ARC), National Headquarters, 2501 Avenue J, Arlington, TX 76006, (817) 640-0204.**

**Association of Birth Defect Children (ABDC), 3526 Everywood Lane, Orlando, FL 32806, (305) 859-2821.**

Center on Human Policy, Syracuse University, 406 Huntington Hall, Syracuse, NY 13210, (315) 423-3851.

Consumers Organization for the Hearing Impaired, Incorporated (COHI), c/o National Association for Hearing and Speech Action, 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255.

Council of Citizens with Low Vision (CCLV), 1315 Greenwood Avenue, Kalamazoo, MI 49007, (616) 381-9566.

Cystic Fibrosis Foundation (CFF), 6000 Executive Boulevard, Rockville, MD 20852, (301) 881-9130, (800) FIGHT CF.

Disability Rights Education and Defense Fund, Incorporated (DREDF), 2212 6th Street, Berkeley, CA 94710, (415) 644-2555 (Voice), (415) 644-2626 (TDD).

Disabled American Veterans (DAV), Post Office Box 14301, Cincinnati, OH 45214, (606) 441-7300.

Epilepsy Foundation of America (EFA), 4351 Garden City Drive, Suite 406, Landover, MD 20785, (301) 459-3700.

Foundation for Children with Learning Disabilities (FCLD), Post Office Box 2929, Grand Central Station, New York, NY 10163, (212) 687-7211.

Joseph P. Kennedy, Jr. Foundation, 1350 New York Avenue, North West, Suite 500, Washington, DC 20005, (202) 393-1250.

Junior National Association of the Deaf (Jr. NAD), 445 North Pennsylvania, Suite 804, Indianapolis, IN 46204, (317) 638-1715 (Voice and TDD).

Mainstream, Incorporated, 1200 15th Street, NW, Washington, DC 20005, (202) 833-1136 (Voice and TDD).

March of Dimes Birth Defects Foundation (MOD), 1275 Mamaroneck Avenue, White Plains, NY 10605, (914) 428-7100.

Mental Health Law Project (MHL), 2021 L Street, North West, Suite 800, Washington, DC 20036-4909, (202) 467-5730.

Muscular Dystrophy Association (MDA), 810 Seventh Avenue, New York, NY 10019, (212) 586-0808.

National Alliance for the Mentally Ill (National AMI), 1901 North Fort Myer Drive, #500, Arlington, VA 22209, (703) 524-7600.

National Amputation Foundation (NAF), 12-45 150th Street, Whitestone, NY 11357, (718) 767-8400.

National Association for Hearing and Speech Action (NAHSA), 10801 Rockville Pike, Rockville, MD 20852, (301) 897-8682 (Voice and TDD), (800) 638-8255 (Voice and TDD).

National Association for Visually Handicapped (NAVH), 305 East 24th Street, 17-C, New York, NY 10010, (212) 889-3141.

National Association of the Deaf (NAD), 814 Thayer Avenue, Silver Springs, MD 20910, (301) 587-1788 (Voice and TDD).

National Council on the Aging, Incorporated (NCOA), 600 Maryland Avenue, SW, West Wing 100, Washington, DC 20024, (202) 479-1200.

National Downs Syndrome Congress (NDSC), 1640 West Roosevelt Road, Chicago, IL 60608, (312) 2236-0416 (In Illinois) (800) 446-3835 (Outside Illinois).

National Down Syndrome Society (NDSS), 141 Fifth Avenue, New York, NY 10010, (212) 460-9330, (800) 221-4602.

National Federation of the Blind (NFB), 1800 Johnson Street, Baltimore, MD 21230, (301) 659-9314.

National Fraternal Society of the Deaf (NFSD), 1300 West Northwest Highway, Mount Prospect, IL 60056, (312) 392-9282 (Voice), (312) 392-1409 (TDD).

National Head Injury Foundation (NHIF), 333 Turnpike Road, Southborough, MA 01772, (508) 485-9950.

National Kidney Foundation (NKF), Two Park Avenue, New York, NY 10016, (212) 889-2210.

National Mental Health Association (NMHA), 1021 Prince Street, Alexandria, VA 22314-2971, (703) 684-7722.

National Multiple Sclerosis Society, 205 East 42nd Street, New York, NY 10017, (212) 986-3240.

National Network of Learning Disabled Adults (NNLDA), Post Office Box 716, Bryn Mawr, PA 19010, (215) 275-7211.

National Organization on Disability (NOD), 2100 Pennsylvania Avenue, NW, Suite 234, Washington, DC 20037, (202) 293-5960, (202) 293-5968 (TDD).

National Society for Children and Adults with Autism (NSAC), 1234 Massachusetts Avenue, NW, Suite 1017, Washington, DC 20005-4599, (202) 783-0125.

National Spinal Cord injury Association, 149 California Street, Newton, MA 02158, (617) 964-0521.

National Stroke Association (NSA), 1420 Ogden Street, Denver, CO 80218, (303) 839-1992.

Self-Help for Hard of Hearing People (SHHH), 7800 Wisconsin Avenue, Bethesda, MD 20814, (301) 657-2248 (Voice), (301) 657-2249 (TDD).

Sensory Aids Foundation (SAF), 399 Sherman Avenue, Suite 12, Palo Alto, CA 94306, (415) 329-0430.

Spinal Cord Society (SCS), 2410 Lakeview Drive, Fergus Falls, MN 56537, (218) 738-5252.

United Cerebral Palsy Associations (UCPA), 66 East 34th Street, New York, NY 10016, (212) 481-6300.

Vision Foundation, Incorporated, 818 Mount Auburn Street, Watertown, MA 02172, (617) 926-4232, (800) 852-3029 (Toll-Free in Massachusetts).

**L. Facility Associations**

**Commission on Accreditation of Rehabilitation Facilities, 101 N. Wilmot Road, Suite 500, Tucson, AZ 85711, (602) 748-1212**

**Goodwill Industries of America, Inc. (GIA), 9200 Wisconsin Ave., Bethesda, MD 20814, (301) 530-6500 .**

**International Association of Psychosocial Rehabilitation Services (IASPRS), 5550 Sterrett Place, #214, Columbia, MD 21044, (301) 730-7190.**

**National Association of Jewish Vocational Services (JVS), 101 Gary Court, Staten Island, NW 10314, (718) 370-0437.**

**National Association of Rehabilitation Facilities (NARF), P.O. Box 17675, Washington, DC 20041, (703) 648-9300.**

**National Easter Seal Society (NESS), 1350 New York Avenue, NW, Suite 415, Washington, DC 20005, (202) 347-3066.**

**National Industries for the Blind (NIB), 524 Hamburg Turnpike, Wayne, NJ 07470, (201) 595-9200.**

**National Industries for the Severely Handicapped (NISH), 2235 Cedar Lane, Vienna, VA 22180, (703) 560-6800.**

**The Region V Study Group 1988-1990:**

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